



Family Experience of the Mental Health System

Findings Compendium



Louis de la Parte
Florida Mental Health Institute

Family Experience of the Mental Health System

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Findings Compendium

Developed by The Research and Training Center (RTC) for Children's Mental Health, Department of Child and Family Studies, Division of State and Local Support, Louis de la Parte Florida Mental Health Institute, University of South Florida, Tampa, funded by the National Institute on Disability and Rehabilitation Research.

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Family Experience of the Mental Health System

of Child & Family Studies, Louis de la Parte Florida Mental Health Institute (FMHI), at The University of South Florida (USF), Tampa, funded by the U.S. Department of Health and Human Services, Center for Mental Health Services, and the National Institute on Disability and Rehabilitation Research from September 1999 – August 2004. The RTC's mission is to increase the effectiveness of services systems for children and youth with emotional disturbances and their families by strengthening the empirical base for such systems.

The Family Experience of the Mental Health System study has had guidance and invaluable input during the course of the study from parents, and other primary caregivers, and youth. A Family Advisory Committee met each year (2000–2003) at the Federation of Families for Children's Mental Health Annual Conference to help refine research questions, develop protocol, discuss preliminary findings, and examine dissemination strategies. We gratefully acknowledge their insight and guidance.

This study is based on interview data collected over two years from thirty families throughout Hillsborough County, Florida. In the face of continuing challenges and uncertainty, these families allowed us into their homes and shared their stories, with great insight, sometimes anger and sadness, and often with humor. They have our gratitude and respect.

The Family Experience of the Mental Health System (FEMHS)

is one of seven major studies at The Research and Training Center (RTC) for Children's Mental Health, Department

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For Children's Mental Health



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(FMHI Series Publication #224)

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Overview

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Introduction to the Findings Compendium

The **Findings Compendium** is designed to provide a brief summary of the Research and Training Center for Children's Mental Health study of the **Family Experience of the Mental Health System (FEMHS)**.¹ The study was designed to meet a need for information from family perspectives about service access and delivery, as well as about specific aspects of services that are most and least helpful. Over a two year period, 30 families, living in Hillsborough County, Florida shared their experiences as they sought services, entered treatment, and remained in or terminated treatment. We believe that by listening to the stories of families and by assessing the comprehensive effects of these experiences, policy makers can better understand the impact of federal, state and local policies on the families they are intended to impact, and front line providers of services and supports can offer more strategic and individualized interventions. FEMHS' holistic approach helps to provide an understanding of the subtleties and complexities of the families' experiences and adds family voices to more quantitatively designed studies.

¹ The Family Experience of the Mental Health System (FEMHS) is one of seven major studies at The Research and Training Center (RTC) for Children's Mental Health, Department of Child & Family Studies, Louis de la Parte Florida Mental Health Institute (FMHI), University of South Florida, Tampa, funded by the National Institute on Disability and Rehabilitation Research from September 1999 – August 2004. The RTC's mission is to increase the effectiveness of services systems for children and youth with emotional disturbances and their families by strengthening the empirical base for such systems.

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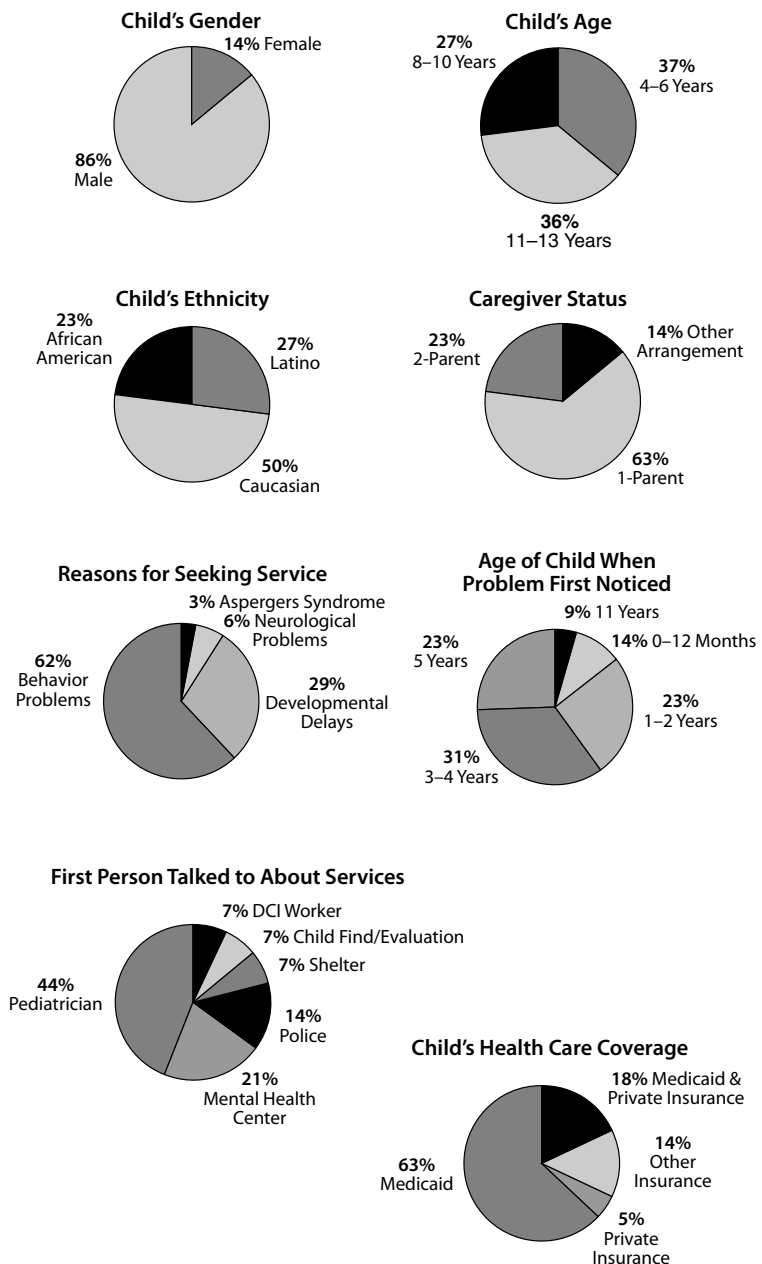
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The Findings Compendium provides information in a series of user-friendly “Findings Briefs” and offers specific “checklists” to summarize findings and their policy and practice implications. The Findings Compendium, also available as a downloadable publication or cd-rom, emphasizes the importance of research utilization. It is our belief that the creation of knowledge and use of information are the motivating force behind all research. Research needs to be accessible to everyone who seeks to improve the lives of children and families, including those most affected, the families themselves.

The thirty families who participated in the study were in the early stages of their search for services for their children. The majority of the children were male (86%), ranging in age from 8 to 13 years old. Fifty percent of the families described themselves as Caucasian, 27% Latino, and 23% African American. Sixty-three percent of the caregivers were single mothers. Most (62%) were seeking mental health services for what they identified as “behavior problems,” and most first noticed a problem before their children were 6 years old (77%). Almost half of the families spoke first to their pediatricians (44%) about their concerns. In most families (63%), the children’s health care coverage was provided solely through Medicaid.

Demographics



Findings Brief 1 Methodology and Attributes

The first brief in this series describes the **methodology** and **attributes** of the study. FEMHS systematically gathered information through interviews with thirty families over an extended period of time, allowing parents considerable latitude in describing their experiences with seeking and accessing treatment services, as well as the services themselves. Naturalistic inquiry offers a valuable tool for creating a space where families are able to speak for themselves. Findings Brief 1 highlights the research partnership with families in all FEMHS activities, including study design, protocol and instrument development, participant recruitment, data collection, data analysis, and dissemination.

Findings Brief 2 Experiences with Medication

Findings Brief 2 examines **caregivers' concerns** and **experiences** regarding placing their children on psychotropic medication to treat a variety of psychological and behavioral problems. Parents expressed fear and uncertainty about the unintended effects of medication, especially on their younger children. Parents were not comfortable with the current knowledge and limited choices associated with psychotropic medication. The findings support the continued need to combat stigma and to develop a targeted education campaign relating to research and dissemination of alternatives to medication, as well as the utility, risks and safety of medications.

Findings Brief 3 Decisions and Responsibilities of Care

One goal of the study was to look at how people make real world decisions. Findings Brief 3 examines caregivers' experiences with **decision-making** and looks at the co-occurring events in family lives that have an impact on their decisions. Families in this study seemed to face some of life's most stressful events at an alarming rate, with caregivers frequently attempting to make decisions concerning multiple problems simultaneously. Families wrestled with life and family decisions with regard to seeking, accessing, engaging in, and continuing with or terminating services and supports for their children, as well as relocation, divorce, employment and health care coverage. The **Cascade Effect** and the **Pyramid of Decisions** illustrate how these experiences often contribute to dramatic changes in families' life situations as they make complex decisions and tough trade-offs in order to provide mental health services for their children.

The commitment and sacrifices made by families in the study to care for their children with serious emotional or behavioral disturbance was great. Many families were persistent in seeking services for their children and struggled for long periods for their children to remain in services and at home. The capacity of a

"I'm saying [this], because someone needs to know."

"I just don't like the guinea pig feeling of all the medications."

"I'm just trying to educate myself at the speed of light, so that I can be very well prepared for my meeting and to make decisions."

caregiver to independently and aggressively seek services was often the key determinant in how and whether a service was identified and ultimately used. Although the literature suggests high “drop out rates” or “non-compliance” with treatment, families did not report dropping out of services altogether, but rather left particular providers for what were reported to be valid reasons, for example: lack of transportation; “impossible” times a provider was available for the family to access a service; a parent’s perception that the service was not what the child needed; a parent not feeling respected or believed; and caregiver strain.

Findings Brief 4 Pathways to Care

For families in the study, the **pathway** to appropriate mental health services is complex, often through other than the “mental health system” (i.e., schools, courts, and pediatricians), and often through informal networks (i.e., waiting rooms, playgrounds, etc.). The **Pathway to Services** illustrates the often complex and multiple paths families must navigate as they seek, obtain and remain in or terminate services. Findings Brief 4 also looks at the increased challenges experienced by Spanish speaking families who participated in the study. Their experiences varied, often depending on language proficiency, and immigration status and permanency.

Findings Brief 5 Helpfulness of Formal Services, Family Organizations and Informal Supports

Findings Brief 5 looks at the ways in which services are helpful to families. Families in the study consistently reported that the greatest aspects of the services they received were: the quality of relationships established between the children and their therapists or case managers; the accessibility and responsiveness of services and providers to the requests and needs of caregivers; the degree to which services were coordinated across providers; and, the extended supports provided that also focus on the entire family (e.g., mentors, respite, transportation, family advocates, information and access to services, sibling support groups).

Brief 5 also examines support from family advocacy organizations, such as the Federation of Families for Children’s Mental Health, other advocacy groups, and informal, natural supports and services. Families liked the information and the support from these groups and often expressed feelings that these groups were the only ones who truly understood their experiences. Many families in the study also turned to friends, family, and spiritual connections for support and guidance. These findings underscore the important roles family and advocacy organizations and informal supports play in a family’s opportunity to learn about mental health services and feel supported in the process.

“I’ve tried to get help by just calling everything. . . a list that the liaison gave me — just dialing numbers. Can you help me? Can you help me? Can you help me?”

“They keep connecting you to other places and send you other places”

“If nothing else, having a therapist for my son gives me some sense of — if this makes sense to you — security.”

“It helps when you can sit in a room full of other people that are going through the same scenario of frustration that you are, that have a clue of what you’re saying, and can say, ‘I know what you’re going through.’

Family Voices Contributing to FEMHS...

...described their experiences, not only in terms of ultimate outcomes, but also with respect to quality of life. Many families experienced constant instability because of major financial challenges, tenuous health care coverage, family health issues, and health care disparities — often associated with their children's emotional problems. These families persevered in seeking help for their children. They displayed enormous strengths in the face of numerous obstacles. What is evident from this study is that, behind most of the children, were one or more parents or caregivers struggling to keep up their sense of hope and their emotional and physical energy, and keep their families together as they searched for solutions to meet the mental health needs of their children. Most families met these challenges with heroic efforts amid consistently high levels of stress. The system can build on this natural resiliency in families by providing them with readily accessible and accurate information and accessible services and supports.



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Findings Brief 1

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Methodology and Attributes

A critical source of information about the impact of policies are the children and families directly affected. This is particularly the case since the perspective of children and families on mental health and related services is not always the same as the perspective of service providers, administrators, and policy makers (Friedman, 1997; Unger & Powell, 1991; Friesen et al, 1992). Moreover, including **family perspective** has been found to improve the quality and effectiveness of service delivery (Reimers et al., 1995; McNaughton, 1994; Ford et al., 1997). Increasingly, research is showing the efficacy of meaningful family involvement in mental health service planning and delivery (Pires, 2002). For example, family partnership is considered a key variable of evidenced-based practice (Burns & Hoagwood, 2002). Of all the stakeholders with an interest in children's emotional and behavioral health, it is the children, youth and families who have the greatest stake (Osher & Telesford, 1996).

Yet, traditional approaches to examining family perspectives are largely cross-sectional and quantitative, relying heavily on the use of standardized measurement instruments and rating scales of consumer satisfaction (Harris-Kojetin et al., 1999). In contrast, the **Family Experience of the Mental Health System (FEMHS)** utilizes a **longitudinal design** employing a semi-structured interview technique. This technique, which uses naturalistic inquiry, offers

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a useful tool for gathering information from families about their experiences seeking services and with the services themselves. The study's **qualitative approach** offers a systematic way of documenting families' experiences without the limitations of more traditional, standardized, quantitative research methodologies.

Seeking to understand, rather than predict or generalize, FEMHS explored family setting and context, capturing the complexities of the experiences and viewpoints of those most affected by policy and implementation, i.e., families themselves (Maxwell, 1990; Patton, 1990).

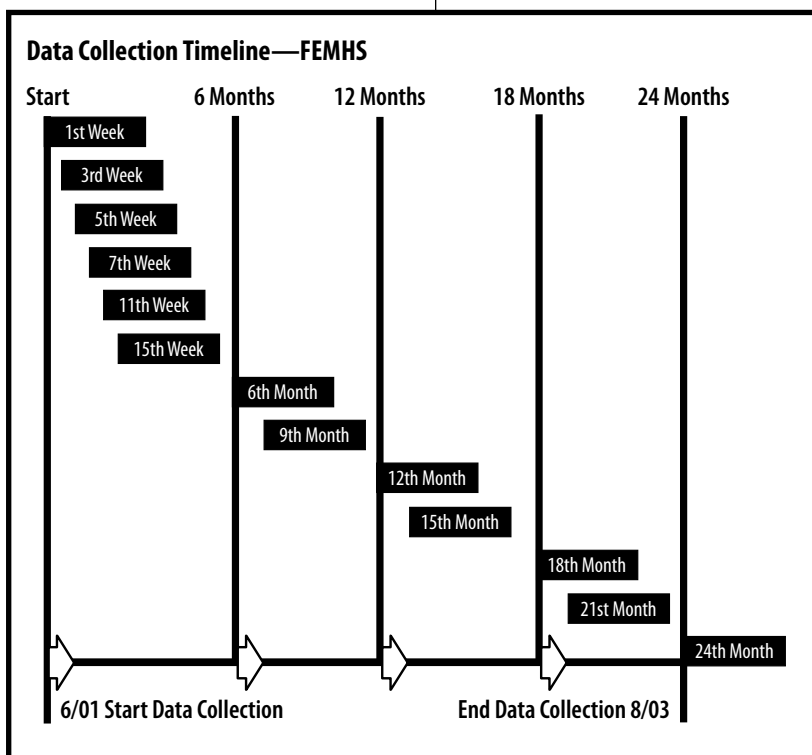
FEMHS followed **30 families** over **two years** as they sought services experienced treatment, and discontinued services. Criteria for participation in the study included:

- Child must be in need of mental health services identified through the school, mental health system, primary care physician, or primary caregiver;
- The child must be between six and 12 years of age;
- The family may or may not be Medicaid eligible, and,
- The family may or may not have had previous involvement with the mental health system.

Twenty-five families, designated as **high frequency**, were contacted in person and by telephone every two weeks the first two months. These families were then contacted by telephone every four weeks for the next two months, then every three months for the remaining 20 months. The initial twelfth month and final twenty-fourth month interviews were conducted in-person. **Five** families, designated **low frequency**, were contacted by telephone the first, twelfth month and final twenty-fourth month. All interviews were audio-taped with the consent of the interviewees, transcribed, coded and placed into a database for qualitative analysis. Participants were paid for each interview.

At the onset of the study, all families participating in the study lived in Hillsborough County, Florida. Data collection began in June 2001 and ended in August 2003.

Seeking to understand, rather than predict or generalize...



Of the thirty families in the study, half identified themselves as other than Caucasian, including those whose first language was not English. It is important to note that the interviewers of the African-American families who participated in the study were not of African American descent. Some studies suggest that African Americans may feel uncomfortable talking about race related issues with non-African Americans (Reese, 2003); therefore, the response from these interviews may have been different if the interviewer was of the same racial background. The interviewer for the Hispanic families who participated in the study was also Hispanic and bilingual.

The **guiding research questions** of **FEMHS** included the following:

- 1) What is the experience of families with children with an emotional disturbance during the period of time between when families first identify a problem with their children and when they “officially” obtain services?
- 2) How do federal policies and programs and local implementation efforts intended to serve children and families actually impact their lives?
- 3) What variables are factored into decisions by families to seek, obtain, remain in or terminate services?
- 4) What services and supports do families find most helpful and why?
- 5) What is the unique experience of families of color who have a child with serious emotional disturbance to seek, obtain, remain in or terminate services?

Specific questions were asked during the thirteen interview points throughout the two years regarding services, the child’s behavior, school placement, the family’s financial situation, employment, housing and living arrangements, health insurance, the child and family’s health, plans for next steps, upcoming appointments, and any other updates the family wished to share.

Data collection tools utilized for the study were first pilot tested by the study team with families who were seeking mental health treatment for their children, or who were in the initial stages of utilizing treatment services. The study team was confident that the final interview protocol, as a result of many revisions, was culturally sensitive and would comprehensively capture the families’ experiences as it related to the experiences of seeking and receiving services for their children.

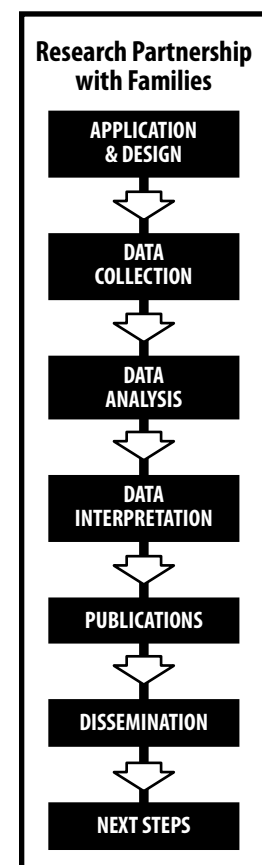
In order to preserve the richness and context of the interview data and increase the validity, reliability and objectivity of the findings, the data were organized and analyzed by a variety of methods, including the use of manual techniques and N-VIVO computer software, a qualitative software program that allows for sophisticated pattern searches within text.

Interviews were audio-taped, transcribed, and then imported into the software program and categorized following a coding list based on the study's research questions. Inter-rater reliability was conducted for coding and found to be reliable at 86.8%. **FEMHS** used a **data transformation approach**. Data transformation is an analysis process that allows for representation of the perspectives of interviewees through a systematic procedure. Information is transformed, step-by-step, from raw data into interpretive descriptions. The process controls the level of interpretation, follows a traceable pattern and increases the level of reliability of the qualitative data. In the **description phase** of the study, the families' experiences are described by extracting themes from the transcribed interviews. Themes are extracted within the context of each study category and each of the data collection waves. Each identified theme is accompanied by corresponding **quotations**, believed by the researcher to best reflect the theme. Once the themes are listed, the analyst, working inductively, then looks for **emergent patterns** in the data within each wave. With the goal to present the families' stories as accurately as possible, the analyst moves back and forth between the extracted themes and the actual data in search of meaningful patterns. Utilizing this process, the study team summarized the findings and identified points of convergence and divergence. (Welsh, 2002; Lazear & Worthington, 2001). Thus, the team returned to the transcripts, the raw data, over and over again as stressed by Patton (1990) "...to see if the constructs, categories, explanations, and interpretations make sense, if they really reflect the nature of the phenomena (pg. 477)."

The findings illustrate the ability of the qualitative approach to gather data that provide a more comprehensive view and accurately reflect the families' experiences with seeking, continuing or terminating mental health services. The longitudinal and qualitative approach taken by FEMHS enabled the contributing families to express their experiences, not only in terms of ultimate outcomes, but also with respect to quality of life.

Timelines were created during the data collection process to review, over time, the experiences of the families. The timeline was updated after each interview, and was reviewed for accuracy with the parent or caregiver during the final interview. For example, the Timeline on page five represents the experiences of a family in six of the ten areas examined over two years, at seven of the 13 data collection points (Waves).

FEMHS incorporated family participation to guide the research process over the five year life of the study. A **Family Advisory Committee** met each year at the **Federation of Families for Children's Mental Health** Annual Conference in Washington, D.C. to help refine research questions, develop protocol, discuss preliminary findings and examine dissemination strategies.



One Family Over Time

	Wave 1	Wave 3	Wave 5	Wave 7	Wave 9	Wave 11	Wave 13
Family Composition & Living Arrangements	Mother, father, 3 children, grandmother			Grandmother moved out	Spouse may move; hasn't been spending nights at home	Filing for divorce;	Divorce papers being served; fears she and the children will be living out of a car
Health Care Coverage	Had private insurance birth-3; no insurance 3-5; Healthy Kids/Florida KidCare (Children's Medical Services) 5-9; applied for SSI; no health insurance for parents	Waiting on SSI determination for eligibility	Waiting on SSI eligibility determination	Waiting on SSI eligibility determination	Denied SSI, but will reapply	Child qualified for SSI	Once divorced, will apply for Medicaid
Formal Services	Seeking services through Dept. of Mental Health, school & mental health center; has referral for psychologist; currently receives services from neurologist, OT; receives WIC services; has been on Ritalin & Dexedrine — now on Zoloft for depression (100mg daily)	OT	Waiting to hear from hospital re: assessment for seizure; OT	OT; Waiting on answer from state re: services; requesting another prescription from pediatrician for psych. services; completed EEG at hospital; mother is seeking psychological and parenting services for herself; threatened to file grievance against mental health center	New pharmacy for medication is further away — 40 miles; child sees psychologist 43 miles away; waiting on functional behavior analysis; sees neurologist, child on anti-seizure meds; auditory/speech services 14 miles away; no longer gets WIC services because discontinued mobile unit; took 7 months to get appointment at mental health center (need went from urgent to crisis); continue to try medications — Ritalin, Concerta, Dexedrin, Depacote,	Receiving help from clinical case manager from mental health center and school mental health worker; therapist at health center; still waiting for functional behavioral analysis; anger management service stopped due to time constraints; OT evaluation said child needed no services; using WIC again; Has speech evaluation scheduled; Speech therapist terminated services because child is too old; no FBA due to psychologist recommendation; decrease services of therapist due to gas costs and child is tired of going to so many appointments; Child has tried Aderol and Meditate without success, is back on Zoloft and Risperdal	Child begins new medication — Strattera; takes Zoloft, Depacote, Risperdal; lost the school based worker because of Medicaid
Informal Services & Supports	Has received information & support from Federation of Families; has no support from spouse	Family Café workshop; contact with STAND; child benefited	Federation of Families; STAND	Spouse if unsupportive about child getting services; lost baby sitter	Trying to get child into YMCA program trying to get respite services; church group	Getting help from Family Network on Disabilities; receiving respite services, very helpful; seeking after school care/day care so mother can return to work; YMCA tutoring; Family Café workshop; grandmother offers to pay for ear doctor for mother	
Child's Behavior	Low self-esteem; hyper and impulsive	Behaviors at home declining; school behavior better	School & home behavior worse	Very depressed	Child got suspended; behavior is worse	Worse at school; stable at home	Still difficult at school and home
School Placement	In regular school (his 3rd placement in two years) — Seeking ESE placement or services; has grievance filed against school	School IEP staffing scheduled; waiting to hear about grievance Paid position with Federation of Families	Requested application for new school; Developed IEP	Contact state about school placement — making phone calls 3 minutes to 3 hours 3 days a week; waiting to hear about scholarship for new school	Trying to get service in the school; grievance is still pending; child went to new private school for two days, got suspended — back in public school, regular classes	Will try to get child into different school next year; child is at new school but having a hard time with many suspensions; gave up on grievance because never heard anything and had so much to do	Unsure of school placement for next year
Employment & Finances	Mother no longer works; father is employed full in construction	Paid position with Federation of Families	Working part time with Federation and community mental health project	Working for Federation only now — asked to be on Board	No longer employed; lots of financial instability; filed bankruptcy	Mother will return to work if can find after school care/day care; seeking child support; back to working for Federation part time, hard to find time	No longer working for Federation; financial situation is not good
	Child diagnosis ADHD, fine & gross motor skill problems, Dysphasia, central auditory processing problems; has been on Ritalin & Dexedrine — now on Zoloft for depression (100mg daily)		Child had 1st seizure in 3 years	Child's EEG is fine; grandfather is very ill; mother is seeking services for herself, both psychological and physical	Other children are having behavior and physical health problems; child broke his foot	Mother has lost hearing in one ear; may have possible skin cancer; doctor has recommended Prozac for mother, but could not afford it, so on Zanax; child broke his foot again; grandfather's health is deteriorating; seeking services for other children	Still looking for services for younger children

System of Care Checklist: Methodology and Attributes

When considering research...

Patton (1990, pg.150) suggests that determination of research methods should be guided by a clarity about the purpose of research, which may include:

- ☐ Basic research to contribute to fundamental knowledge and theory;
- ☐ Applied research to illuminate a societal concern;
- ☐ Summative evaluation to determine program effectiveness;
- ☐ Formative evaluation to improve a program; and
- ☐ Action research to solve a specific problem

Yin (1984, pg. 13) proposes three questions when developing the research question:

- ☐ What is the form of the research question — is it trying to explain some social phenomenon or is it exploratory, seeking to describe the incidence or distribution of some phenomenon?
- ☐ Does the research require control over behavior, or does it seek to describe naturally occurring events?
- ☐ Is the phenomenon under study contemporary or historical?

Marshall & Rossman (1989, pg. 31) suggest answering the following questions when describing the framework for research:

- ☐ Who has interest in this domain of inquiry?
- ☐ What do we already know about the topic?
- ☐ What has not been answered adequately in previous research and practice?
- ☐ How will this new research add to knowledge, practice, and policy in this area?

Marshall & Rossman (1989, pg. 23) suggest that a research proposal must answer the following questions:

- ☐ Does the proposal demonstrate a link with the research model?
- ☐ Who might care about this research? To whom will it be significant?
- ☐ How will the researcher conduct this research?
- ☐ Is the researcher capable of doing this research?

Maxwell (1990) suggests qualitative research methods can meet the needs of the field in multiple ways by:

- ☐ Identifying unanticipated factors influencing situations and issues;
- ☐ Enabling researchers to study the complexities of life experiences;
- ☐ Giving a holistic picture of the phenomenon studied;
- ☐ Incorporating the perspectives of the people studied; and,

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Findings Brief 2

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Family Experiences with Medication

Over a period of two years, thirty families shared their experiences as they sought services, entered treatment, and remained in or terminated treatment. During those two years, in 13 separate interviews, the parents and caregivers who participated in the study were asked about their experiences with medication.

Psychiatric medication was one of the interventions that many of the children in the study were offered and/or tried. For many families in the study, the child's pediatrician was the first to prescribe psychotropic medication. Most of the children taking medication were prescribed anti-depressants, specifically Selective Serotonin Re-uptake Inhibitors (SSRIs), such as Adderall/Adderall XR, Zoloft, Effexor, Paxil, and Strattera. These agents were prescribed to treat a variety of psychological and behavioral problems, including depression, inattention, and aggression. A few children were taking multiple medications to address a wider variety of symptoms. In addition, most children had tried multiple medications and varied dosages over time, with it proving difficult to find an agent that effectively addressed the intended symptoms without producing intolerable side effects. On page two, Mrs. Brown reports on her son Trevor's — names changed to ensure confidentiality — experiences with medications, which reflect those shared by many families interviewed as part of the study. During this two-year period Mrs. Brown also had another child on a medication regimen.

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Mrs. Brown Reports on Her Son Trevor's Experiences with Medications

Prior to moving to Florida, Trevor, age 16, was seeing a psychiatrist in another state. He had been on and off **Risperdal**. Mrs. Brown reported that her son, Trevor, is very sensitive to medication. She said that his new psychiatrist (private pay) would like to place him on new medication, but Trevor would need to be "detoxed" first, but there are no local hospitals to do this. Trevor has been on **Zoloft**. His dosage was recently increased from 100mg to 150mg. Trevor was also prescribed 200mg of **Welbutrin**. He was "in a trance" so after two days, his dosage of **Zoloft** was decreased to 100mg.

Mrs. Brown reports that Trevor is tolerating the reduced dosage of **Zoloft** so the psychiatrist is rethinking the need to "detox" him. The pharmacy has made repeated errors (dosages) on the prescriptions. Trevor is no longer taking **Ritalin**, because it stopped the normal course of puberty, but they will restart it before school. With the summer here, Mrs. Brown says that Trevor is not taking medications regularly, or is taken reduced dosages, 30mg of **Zoloft**. The psychiatrist (through Children's Medical Services) at the mental health center tells Trevor he may be able to do without the medication.

No Contact

Although Trevor's behavior has stabilized, he continues to have problems with bowel obstruction and also reflux issues. Mrs. Brown reports being worried about being able to continue the medication management through the (private pay) psychiatrist, whom she likes and trusts.

Mrs. Brown reports that there has been a very negative change in Trevor's behavior at school and at home. She believes it is a result of his bowel obstruction that has worsened. She is thinking Trevor may benefit from the same type of medication that has helped her and Trevor in the past—**Effexor**. Trevor's medication dosages have increased as a result of his worsened behavior—100mg of **Zoloft** and 75mg of **Effexor**. Mrs. Brown reports that the psychiatrist, before moving to Florida, warned her that these medications lift the levels of some chemicals in the body and may cause some reckless behavior, which Trevor displayed when he was on the combined medications in the past. Mrs. Brown contacts Trevor's old psychiatrist and is told that it is a mistake—the **Zoloft** should be dropped to 25 or 50 mg, not raised to 100mg.

Mrs. Brown reports that Trevor is doing well. She says his behavior is stable and there have been no changes in his medications.

No Contact

Trevor was "groggy" in school so his dosage of **Welbutrin** was decreased to 100mg and his dosage of **Zoloft** was increased to 125mg. Mrs. Brown reported that Trevor has side effects from the medication, blocked bowels. He is given **Paxil**, which seems to be related to his loss of control of both kidneys and bowels.

Mrs. Brown reports that Trevor is going through hormonal changes and medication adjustments are necessary. She says Trevor only gets **Ritalin** once a day, except when someone is coming over or they are going out in public, then it's twice a day. There is still some discussion with the psychiatrist about "detoxing" Trevor, although it looks more like they will not because it seems the medication is right now and his behavior is improving. Meanwhile, the psychiatrist at the mental health center decided Trevor did not need **Ritalin** and put him on **Concerta**, saying that it was just as good as **Ritalin**. Trevor's behavior worsens, but the psychiatrist would not listen. He told her not to buy "resold" **Ritalin** at the school. Trevor also tells the doctor that he is much better on the **Ritalin** than the **Concerta**.

Mrs. Brown reports that Trevor continues to have problems with his bowels and reflux issues and is waiting on the results of his colonoscopy. His behavior is stable. Trevor is on **Zoloft**, **Risperdal**, **Welbutrin** and **Ritalin** (no longer **Concerta**).

Mrs. Brown reports that Trevor is no longer taking **Welbutrin** and increased the dosage of **Zoloft**. He is also taking a minimum amount of **Effexor** since he continues to have bowel problems. Trevor's aide in school has also let Mrs. Brown know that she is worried that Trevor is going blind.

Mrs. Brown says she is worried because Trevor has a diagnosis of **Usher's Syndrome (Retinitis)**. She reports Trevor is now on 90mg of **Ritalin** only.

Mrs. Brown reports that Trevor is taking **Risperdal**, **Ritalin** and **Zoloft**. She fears that Trevor may not be eligible for Medicaid when he turns 18 and has no idea how they will pay for his medications. They are not sure if they will be able to continue seeing the private pay psychiatrist. She reports that Trevor continues to have bowel problems and also had a bad cold and cough that wouldn't clear up. Mrs. Brown and the doctor were concerned about putting him on antibiotics, so they gave him a homeopathic remedy and some sinus and allergy medication. Mrs. Brown reports that it interacted with his medications and for four weeks he was "off the wall." She said Trevor was given an antibiotic, his medications reduced during that time, and then returned to previous levels.

Parents expressed numerous concerns about medications. For example, one parent declined to continue pursuing yet another medication because she felt her child was being used as a “guinea pig.” One family experienced a setback when adjusting medications and found that, while the adjustment improved one health problem, it exacerbated another. The longitudinal design of the study, however, also allowed the investigators to see a transformation in outlook among some of the primary caregivers regarding medications as more information was made available to them and their children experienced successes.

Several families had more than one child with special needs receiving pharmacological therapies. For at least four of the families, cost would have been prohibitive were private insurance or public assistance not available to them. Families reported that even with insurance, out-of-pocket medication costs for a single child were between \$200 and \$270 per month. With no insurance available, one parent had to charge medications for two years. Another parent also reported that, while insurance did cover 80% of most medicines, their insurance did not offer any coverage on some very expensive medicines. Financial difficulties were experienced by many of the families with children whose treatment included a program of psychotropic medication.

The degree to which medication was reported to benefit the children in the study varied a great deal. Some caregivers reported that the use of medication resulted in an improved ability on the part of their children to think and reason, a reduction in aggression, and better control over behaviors in general. These benefits translated to functional improvements at home and in school. In contrast, some caregivers reported that medication did not produce any noticeable improvement. At worst, the side effects of the medication outweighed the benefits, with caregivers reporting that their children became overly sedated, hyperactive, suffered cracked lips, or a loss or increase in appetite.

In some instances, caregivers were hesitant to allow their children to be medicated. They expressed concern about the side effects, the lack of data supporting the use of these medications in children, fear based on their lack of knowledge about their child’s potential response, and the number of people prescribing medications for their child. Based on these concerns, a few caregivers routinely started and stopped their children’s medication at will, without consulting the prescribing physician. In addition, not all children received their medication regularly, which may have had an impact on the effectiveness of the medication.

Seven African American and eight Hispanic families participated in the study. While their experiences with medication varied depending on their ethnic/racial background, language proficiency, education, and immigration status and permanency, many of

“We don’t know what we’re doing. We’re just playing with it again. Same as usual.”

“I know what Depicote has done to his teeth and gums. . .that’s the visible, but what’s in there, inside him. . .to me every six months a blood level check is not really good enough to satisfy my fears.”

“I never saw the difference [with the medication] to begin with.”

“He starts this week with a new medication called Strattera. I don’t know anything about the medication. It’s brand new from January. It’s not very well tested, not FDA approved [for children] and it’s for adults. I don’t like the guinea pig feeling. . .”

their experiences mirrored those of other families in the study. For example, Hispanic families had a difficult time giving so many medicines to their children. 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 changes often took place without prior authorization from the physician.

According to some families, local, state and national policy changes affected the medication issues for the participating families. Aside from the cutbacks in programs that caused interruption of insurance coverage or prescription coverage, one family reported a county policy that required that medications be obtained at a particular pharmacy at the opposite end of the county from where they lived. Another family experienced a delay in receiving prescribed medication because it had to be special-ordered. In the face of uncertainty and limitations of health insurance coverage, some families were forced to delay needed medication for their children.

What the Research Says

Today's treatment for emotional and behavioral disorders in children may combine psychotherapy, supportive services such as special education or social skills training, and pharmacological therapy. Families are often placed in situations where a medication regimen is the recommended treatment for their child. Children are coming into mental health care with prescriptions from their pediatricians and neurologists for various conditions, such as attention deficit hyperactivity disorder (ADHD), depression, and asthma. Treatment plans document psychiatric or psychological assessments that frequently result in a child receiving medication for treatment of a behavioral disorder. Nationally, the total expenditures on psychotropic medications for children in 1998 were estimated to be \$1.1. billion (Ringel & Sturm, 2001).

The Surgeon General's **Supplement to Mental Health (2001)**

"...encourages people with mental illness, regardless of race or ethnicity, to take advantage of scientific advances and seek effective pharmacological treatments for mental illness" (pg. 37). Studies show positive benefits of some psychotropic medication being reported by families, with evidence indicating the merit of most of these interventions in treating some behavioral disorders, such as ADHD, when properly used and monitored (Findling et al., 2002). According to some estimates, as many as 80–90% of children and adolescents with ADHD will respond favorably to medication, although the response rate is somewhat lower for preschoolers (Rapport et al., 1994; Hughes et al., 2001). Multimodal treatments, treatments in which pharmacological and psychosocial interventions are used in concert, are also reported to attain positive results with diminished dosage of drug therapy over time (Green, 2001).

Still, there is recent controversy over prescribing psychotropic medications for children as is reflected in current reports and in the literature. For example, the **National Alliance for the Mentally Ill (NAMI)**'s recently released **Report on Children and Psychiatric Medications** recommended making children a priority and that **NIMH (National Institute for Mental Health)** increase research focused on the early onset of mental illness and long-term studies of the use of psychotropic medications in children. NAMI medical director, Dr. Kenneth Duckworth stated,

"Life is uncertain. Risks are real and must be carefully weighed. But sometimes the worst risk lies in doing nothing" (National Alliance for the Mentally Ill press release, 2004).

The President's **New Freedom Commission on Mental Health Report** states,

"Breakthroughs in developing the next generation of medications provide hope for treatment and recovery from mental illness. . . However, since these medications are treatments and not cures, some individuals with chronic illness, including children, are expected to use these medications over an extended period of time. . . long term effects have not been studied well enough for many psychotropic medications" (pg. 70-71).

Greenhill and Associates (2003) identified obstacles and special challenges faced by investigators who conduct psychopharmacological studies in preschoolers. They concluded that with preschoolers being increasingly treated with medication for emotional and behavioral disorders, current and future research must address the safety and efficacy of these psychopharmacological treatments. Many families and treatment providers remain cautious.

Caregivers often express concerns about placing their children on medication. Parents are frightened and unsure of the intended and unintended effects of medication, especially on their younger children. Parents are not comfortable with the current knowledge about psychotropic medications and current choices for treatment (Barrett & Ollendick, 2000; Lazear & Worthington, 2001). Issues with adherence, the extent to which caregivers and children agree with and follow through with the recommendation of the physical or behavioral health care provider, are reflected in the literature. In addition, with health insurance coverage tenuous for many families, parents report struggling to purchase medication prescribed by the child's psychiatrist, and being forced to "stretch" medication over the course of the month to make it last longer (Lazear & Worthington, 2001).

Cultural beliefs about the utilization and effectiveness of medication must also be understood, along with a family's previous experiences with health delivery systems (Canino & Spurlock, 2000). Culture matters because it affects:

- Attitudes and beliefs about mental health;
- The expression of symptoms;
- Coping strategies;
- Help-seeking behaviors;
- Responsiveness to treatment;
- The utilization of services; and,
- The appropriateness of services and supports (Gibbs & Huang, 2001).

There is, however, a lack of research addressing the differences of the effects of psychotropic medication on ethnically, racially, economically, or socially diverse groups of children. There is some data to suggest ethnicity and non-biological factors can affect the response to psychopharmacotherapy — specifically, the non-biological factors that may affect compliance with a medication program, the intensity of the placebo effect, and the reporting of positive or negative effects (Poland & Lin, 1993; Smith et al., 1993). The Surgeon General's Supplement to Mental Health (2001) reports the existence of striking disparities for minorities in mental health care and the underlying knowledge base and reported that minorities do not yet completely share in the hope offered by scientific advances in understanding and treating mental disorders.

Based on the experiences of the families in the study, as well as evidence-based and promising practices the checklist on the following page can help guide the development of systems of care as they address issues of medication. There is a continued need to combat stigma and to develop a targeted education campaign related to research and dissemination of alternatives to medication, as well as utility, risks and safety of medications.

System of Care Checklist: Family Experiences with Medication

- ☐ Clinicians individualize therapies, and medication regimens, according to the age, gender, culture, ethnicity, and other life circumstances of the child and family.
- ☐ Physicians and health practitioners are aware of and incorporate into treatment the cultural beliefs about mental health, the effectiveness of psychotropic medication, and the use of alternative medicines and folk beliefs for children and youth and their families to whom they provide services.
- ☐ Care coordinators are aware of and incorporate into service planning the cultural beliefs about mental health, the effectiveness of psychotropic medication, and the use of alternative medicines and folk beliefs for children and youth and their families to whom they provide services and supports.
- ☐ School officials and necessary staff are encouraged to be involved in medication management as they often play a supportive role in helping to detect signs of significant behavioral problems or side effects from medication.
- ☐ System of care partners, such as therapists, doctors, case managers and teachers, investigate the rationale behind non-compliance with medication regimens when it occurs.
- ☐ Prescribing physicians are aware of the availability of certain prescriptions, and plan temporary remedies when access may be delayed.
- ☐ Physicians and other child-serving professionals support parents in making decisions on the use of psychotropic medications through informed consent, based on risks and anticipated benefits.
- ☐ Parents are partners in the management of medication prescribed for their children and are kept well informed during the process of identifying the proper medication and dosage, and its effectiveness.
- ☐ Families are informed of and understand the right of parental choice, and the right of access to effective treatments.
- ☐ Legislators and policy-makers consider the scientific evidence and the needs of children with serious emotional disturbances above the transitory controversies when passing legislation or revising policies.
- ☐ A community-based education campaign is on-going to combat stigma and provide education about the utility, risks and safety of psychotropic medications and medication alternatives.

- ☐ Pediatricians and specialty mental health providers communicate and coordinate with one another, other necessary team members and the family about the medications they are prescribing to children.

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Findings Brief 3

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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."

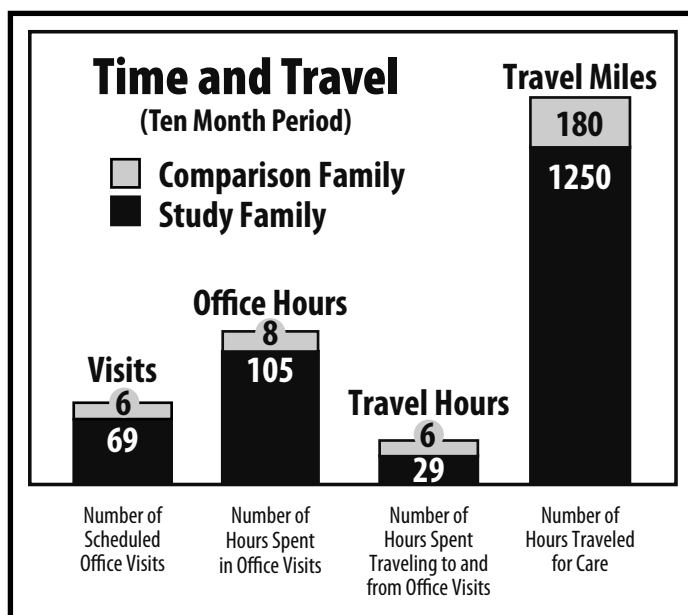
"Her teacher last year wanted to put her in an EMH class. And I refused. I wanted her to have a regular kindergarten curriculum."

"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



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).

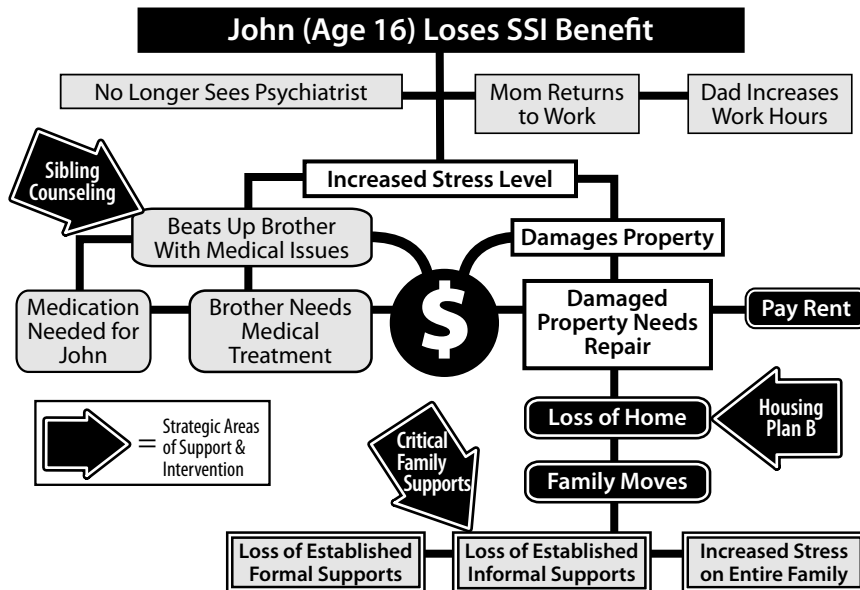
It is also impossible to separate decision-making from issues regarding access and barriers to treatment. Research is increasingly examining the perception of families about barriers to participation in treatment (Kruzich et al., 2003). Kazdin and associates (1997) produced a comprehensive list of barriers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



In the **SSI Family Impact Study**, changes in the SSI benefit policy affected 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

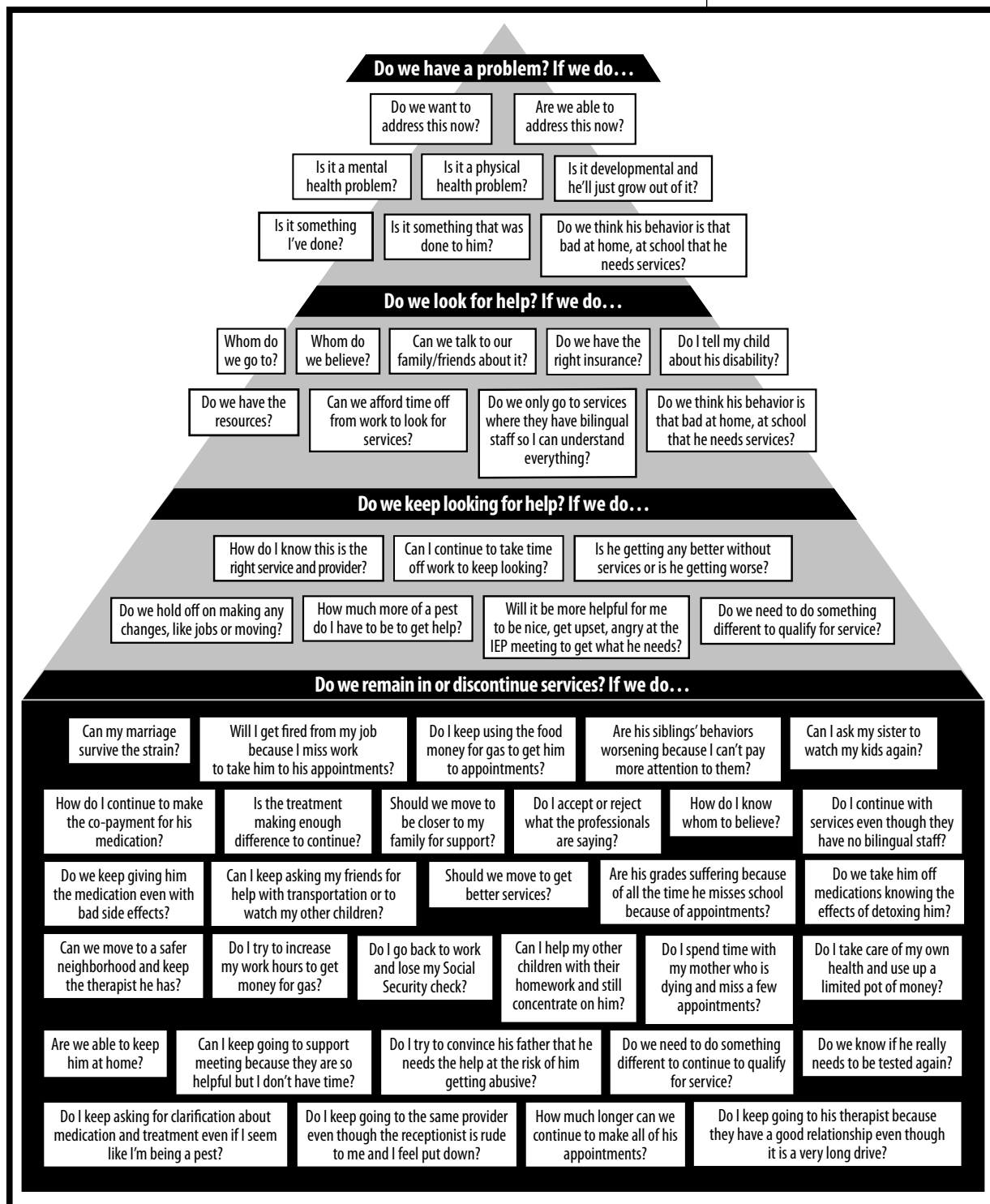
make (Sue et al., 1991; Takeuchi et al., 1993; Viale-Val et al., 1984). These disparities exist even when insurance status, income, age and severity of the condition are comparable (Nelson, 2002). Tokarski (2002) explains one of the reasons for this disparity is that while multi-generational poverty 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



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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Findings Brief 4

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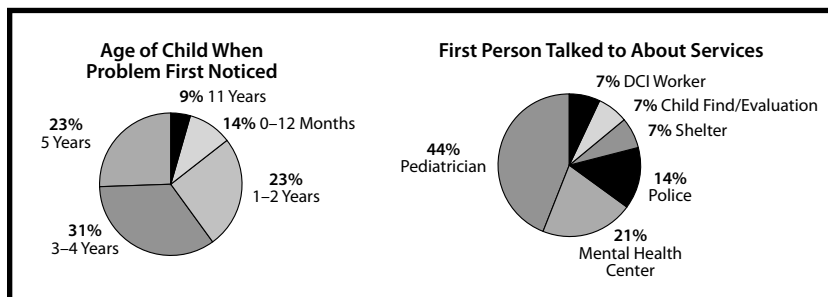


Pathways to Care

"You call here. You call there. And, then you got to call somewhere else."

There was no clear pathway to services for most of the thirty families who participated in the **Family Experience of the Mental Health System Study (FEMHS)** over the two-year period. Families reported multiple pathways to mental health services, with schools, specialty mental health providers, and physicians representing the key initial points of contact.

Although over 50% of the caregivers indicated that they noticed a problem with their children before age four, all families in the study were still seeking services even though the average age of the children when the study began was 9 years old. Sixty-two percent of families first sought services because of their children's behavior problems, with almost half of caregivers (44%) first talking to their pediatricians about their concerns.



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While most caregivers were able to make some initial contact with special mental health providers (e.g., a community mental health center, individualized education planning process (IEP) or school based mental health team), families reported that they lacked information about the services these agencies or programs provided. As a result, they often called or visited multiple agencies before finding the help they needed. Where a family went after this initial point of contact and where they went to find information and sources of referral was often much more complex, with caregivers frequently hearing about these sources through word of mouth or happenstance.

Service referrals generally proved difficult to pursue, and families reported very limited choices, further complicating the pathway to services. Physicians would provide referrals for specific services, without offering the names of individuals or agencies that provide those services. Caregivers were often left to search for service providers on their own in order to follow through on the referral. Even when a specific referral was offered, caregivers would make contact only to learn that they did not provide the service, there was a long waiting list, or their children were not eligible.

Among the study sample of thirty families, the study included seven African American families and eight Hispanic families. For the Hispanic families, their experiences with the pathways to care varied depending a large part on their language proficiency and immigration status and permanency.

The African American families said they did not experience any problems due to their race. However, they, and a number of other families in the study shared their feelings about being discriminated against by some providers or agency receptionists based on their low income or perceived lack of education. It should also be noted that the interviewers were not of African American descent. In one study, results suggested African Americans may feel uncomfortable talking about race related issues with non African Americans, therefore the response from these interviews may have been different if the interviewer was of the same racial/ethnic background. (Reese, 2003)

For Spanish-speaking families, this process was much more difficult, due to the language barrier and the lack of consistent translation services. Those families who spoke Spanish only talked about the difficulties in obtaining services from mental health providers in their own language. They talked about how they had to wait longer periods of time in the waiting room while an office manager or another staff member at the location was able to translate for them. They also mentioned that they sometimes preferred not to call and leave messages for providers since nobody ever returned their calls, and if they did, they answered after several weeks. Other families mentioned that they had to schedule interviews at the school

"And the referrals and numbers; they keep connecting you to other places and send you other places. You call here, you got to call there, and then you got to call somewhere else."

"I'll be taking him however many times a week to a psychologist. I have a referral from the pediatrician, but no place to take him yet."

"Are you trying to say that the White people get help quicker than the Black? I think its so much red tape in trying to get help for anybody because they've always got the dollar sign on it or you ain't got enough money."

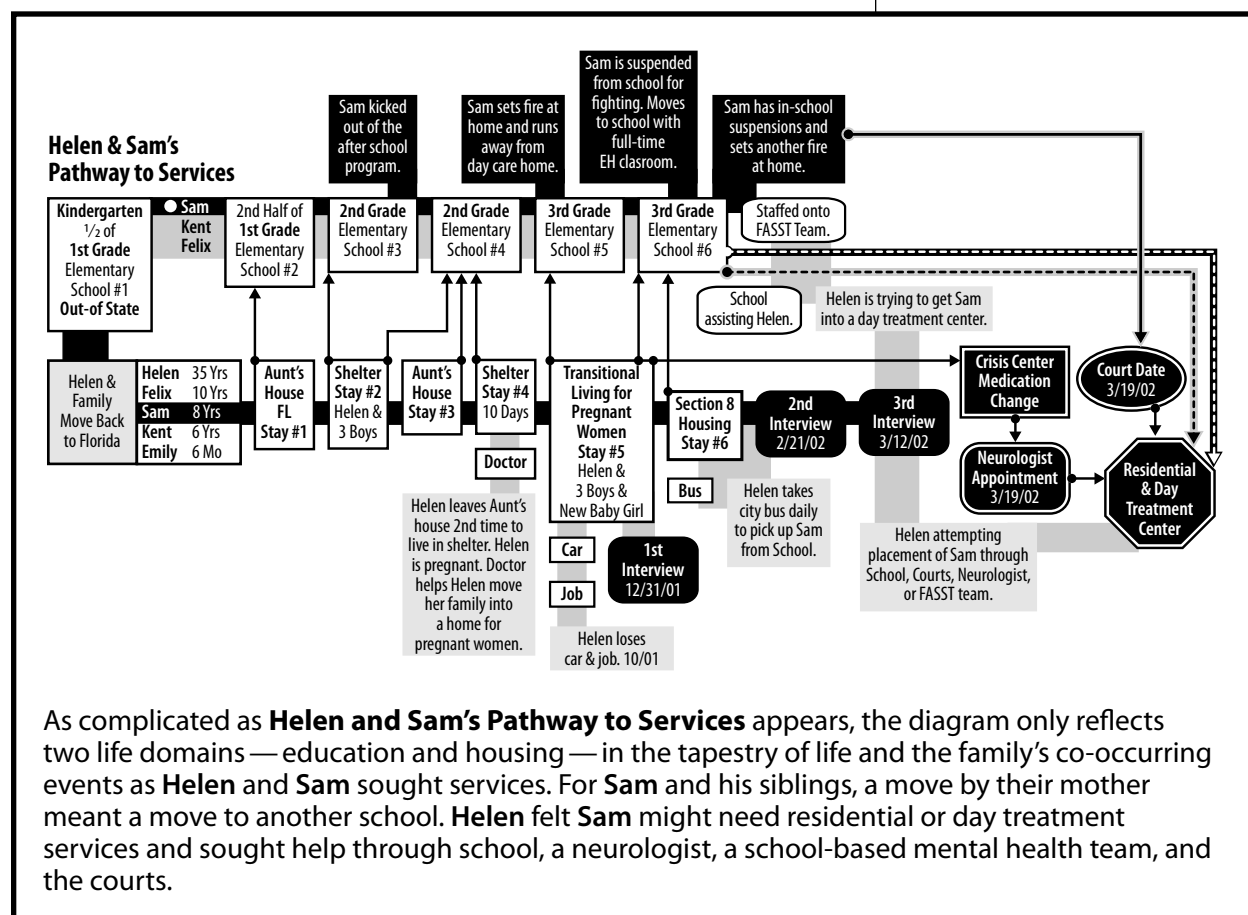
when a bilingual friend was able to go with them. One mother quit services due to lack of a bilingual staff person at the agency. She explained that she understood the difficulties of using her child to do translations and tried not to use her, since she knew sometimes the child did not tell her the truth about what the provider said regarding the child's condition or behavior.

Hispanic families also mentioned they felt they are sometimes discriminated against because of their accents. And, for those who were bilingual, most were depended on for translating and acting as liaisons for other Hispanics. One mother said she likes to help people, but sometimes organizations ask her to volunteer because she is bilingual. She shared with her interviewer that she was helping a lot of families and providers and not getting paid for it. This mother quit volunteering or accepting services from the organization after two years of involvement.

The pathway to services is often complicated by life's co-occurring events. For example, many families moved more than once during the two years of the study within the same city, requiring children to move to other schools and obtain different service providers.

"The social worker's supervisor came home with the therapist. I asked for a bilingual social worker and the supervisor said they didn't have one in my area. She said it was my choice to leave the program since they couldn't give me one."

"I don't have an accent so I have no problem, especially on the phone. There is a problem with that though, because my mother faces it when she goes to certain places. It has to do with the language, especially if a person carries a strong accent. They get discriminated against. It's something that you witness wherever you go."



As complicated as **Helen and Sam's Pathway to Services** appears, the diagram only reflects two life domains — education and housing — in the tapestry of life and the family's co-occurring events as **Helen** and **Sam** sought services. For **Sam** and his siblings, a move by their mother meant a move to another school. **Helen** felt **Sam** might need residential or day treatment services and sought help through school, a neurologist, a school-based mental health team, and the courts.

Families moved for several reasons. Some moved within the same area looking for safer neighborhoods or to be closer to other family members. In any case, a move often included a change in service provision. The family who quit services after being unable to be assigned to a bilingual worker did so after moving to a new location within the same city where bilingual staff was unavailable. Another mother opted to send her children back to her native country since she felt it was easier, faster and less expensive to get services there than waiting for the assessments to be done here in the US.

There appears to be no clearly defined mental health system through which families can access services. Mental health needs to do a better job of establishing itself as a mainline system of care, reinforcing the importance of incorporating education about mental health services to address stigma, and about the relationship of cognitive, physical and emotional development.

What the Research Says

A goal for the behavioral health community has been to provide a more organized pathway to services and supports rather than the often fragmented delivery systems families too frequently navigate. An organized pathway does not necessarily mean a single point of entry or multiple points of entry into a service or system of care, but rather an approach whereby families do not have to navigate multiple systems to obtain care and re-navigate systems every time services and supports require change (Pires, 2002). The delivery of behavioral health services to children and youth and the pathway to care are subjects that have received closer scrutiny in recent years (Sayal et al., 2002; Pescosolido, 1997). Goldberg & Huxley's (1980) **pathways to care model** for psychiatric services, Rosenstock's (1966) **health belief model**, and Andersen's (1968 & 1994) **socio-behavioral model** have helped to conceptualize the processes and activities of seeking services. However, studies continue to show that most children who are in need of behavioral health services do not receive them (Burns et al., 1995; Leaf et al., 1996).

Findings from the FEMHS study suggest that professionals who serve children in everyday settings, such as in schools and health centers, as well as lay people involved in neighborhood activities (e.g., police officers, coaches, recreation counselors) are increasingly being called upon to identify youth with possible mental health problems and to play a role in seeking help for these youth. Stiffman and associates (2000) found that professionals who come into contact with youth are most likely to refer youth for mental health services when they feel capable of making a mental health assessment of the child, and when they are familiar with the mental health services available in the community for that child. In assessing the public's recognition of mental disorders and their beliefs about various treatments, Jorm and associates (1997)

concluded that in order for mental disorders to be recognized early in the community and appropriate intervention sought, the level of mental health literacy needs to be raised, including the understanding of psychiatric treatments.

Over half of the families in the FEMHS study sought help from their pediatricians. This finding reflects current research that most children with psychosocial problems are diagnosed and treated by primary care physicians rather than mental health specialists (Gardner et al., 2000). These studies note that rates of primary care physicians identifying mental health problems in children are low, and, more than half of the children who are referred to specialty mental health by their primary care physician never make it to the specialist (Kelleher, 2000). For this reason, The **President's New Freedom Commission on Mental Health (2003)** emphasized the need for better coordination between mental health care and primary health care, and the U.S. Surgeon General has specifically called on pediatricians to improve screening and referral for child mental illness.

It also should be noted that other studies, including the FEMHS, found that medical personnel do not constitute the major source of referral to mental health services for children and adolescents (Jaffa & Dezser, 1989; Gullotta & Noyes, 1995). Children are referred to mental health services through a much broader referral base, for example, through social workers and schools. This is different from referral pathways for adults, where the likely referral to a mental health service comes from a general medical practitioner. Studies also find that schools are the primary providers of mental services for children (Hoagwood & Erwin, 1997)

The pathways to care for mental health services for children are diverse and are dependent on sociocultural and economic factors. Mental health utilization varies across racial/ethnic groups, and the reasons for these disparities are being more closely examined than ever before. For example, according to **A Supplement to Mental Health: A Report of the Surgeon General (2001)**, racial and ethnic minorities have less access to mental health services than do whites and are less likely to receive needed care. This report identified a number of barriers to care for racial and ethnic minorities including: cost of care; societal stigma; fragmented organization of services; clinicians' lack of awareness of cultural issues, bias, or inability to speak the client's language; clients' fear and mistrust of treatment; and, minorities historical and present day struggles with racism and discrimination, which affect their mental health and contribute to their lower socioeconomic, social, and political status.

Research is increasingly focusing on specific racial and ethnic populations, as well as service use differences between families living in urban and rural areas (Angold, et. al, 2002). For example, Ringel and Sturm (2001) found that Latinos are the least likely of all groups to access specialty care, even though they and Black

children have the highest rates of need. They found reasons for the disparity include mistrust of the health system, language barriers and lack of insurance, with 30% of Hispanics likely to be uninsured. Research finds that people with health care coverage have greater access to services than those who do not (Newhouse, 1993). In a study of African American and Caucasian children, Bussing and associates (2003) found that potential barriers to services included no perceived service needs, system barriers, negative expectations, stigma-related, and financial barriers.

The **President's New Freedom Commission on Mental Health (2003)** specifically addresses the need to improve access to quality care and services by transforming the mental health service delivery system by "providing service and treatment that is consumer friendly and family centered, and by focusing on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery and on building resilience, not just managing symptoms" (pg. 5). Mental health reaches into every avenue of a child's life, and it will take every avenue — education, community, spirituality, work, recreation — to help create pathways to mental health care that are effective and efficient. Research needs to continue to examine factors that influence access to care, increase our understanding of help-seeking behaviors, and provide guidance as community systems of care are built to address the mental health needs of children and their families.

System of Care Checklist: Pathways to Care

- ☐ Families know who and how to call to access service for their child with mental health needs.
- ☐ All aspects to accessing services are culturally and linguistically competent.
- ☐ Families are treated with respect and regarded as experts in knowing their children.
- ☐ Pediatricians and other initial points of contact and referral are aware of services and can make an accurate referral recommendation to the family for further mental health assessments.
- ☐ Eligibility requirements for specific programs are very clearly communicated to families and referral sources.
- ☐ Policies are in place that help systems of care, with multiple service providers, create clear service pathways.
- ☐ Policies are in place to ensure that every child in need of mental health service is able to access them.
- ☐ Policies are in place that can help families, agencies and providers address the racial and ethnic disparities in mental health service utilization.
- ☐ Current or proposed changes to mechanisms, such as managed care, designed to organize, deliver, and pay for health services need to increase access to care and promote evidence-based quality care, emphasizing prevention.
- ☐ All families have access to mental health services without having to navigate multiple systems.
- ☐ All families are able to make changes to service or treatment plans without having to re-navigate the system.
- ☐ Policies are in place to support establishing mental health as a mainline system of care, reinforcing the importance of incorporating education about mental health services, services to address stigma, and about the relationship of cognitive, physical and emotional development.
- ☐ Professionals who serve children in everyday settings have access to current information about mental health and mental health services and treatment.
- ☐ The pathway to care for mental health services recognizes and responds to socio-cultural and economic factors.
- ☐ Barriers to care are identified and appropriately responded to.
- ☐ Creating effective and efficient pathways to services is seen as a community responsibility, including the schools, courts, child welfare, and physical and behavioral health.

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Findings Brief 5

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Helpfulness of Formal Services, Family Organizations and Informal Supports

Thirty families, over a period of two years, shared their experiences as they sought services, entered treatment, and remained in or terminated treatment. During those two years, the parents and other caregivers who participated in the FEMHS study were asked in thirteen separate interviews about the helpfulness of formal services and informal supports. The degree to which formal services were helpful to families in this study varied. Caregivers' perceptions of the degree to which services were beneficial was based on how well the service met an identified need, as well as the quality of the caregivers' interactions with specific agencies or individuals providing services. However, caregivers consistently identified the following aspects of services as critical variables as to whether services are beneficial:

- The quality of the relationship established between one's child and his or her therapist(s) or case manager(s);
- The accessibility and responsiveness of services and providers to the requests and needs of caregivers;
- The degree to which services were coordinated across providers; and,

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- The extended supports provided to the whole family (e.g., mentors, respite, transportation, family advocate, information and access to services).

The abilities of therapists to establish rapport with the children they served was predictive of caregivers' perceptions that therapy was beneficial, while changes in therapeutic personnel were almost always perceived as a negative aspect of services. Effective coordination of services was characterized by good communication across providers and the involvement of caregivers in identifying needs and making decisions concerning their children's care.

Services were not perceived as being beneficial when they did not address an identified need or there was no discernible difference in a child's behavior. Caregivers also became frustrated when appointments and assigned caseworkers or counselors were repeatedly changed and when services were not provided on a regular or frequent enough basis to generate change. Lack of recognition by a provider of a specific problem or need also resulted in frustration, as did providers making a decision to stop services.

Examples of Service and Service Provider Characteristics

+ Helpful	– Not Helpful
+ Good relationship with child	– Service does not address need
+ Provider/agency responsive to request of caregiver	– Appointment times are changed
+ Provides support to entire family	– Provider is constantly changing
+ Services meet needs	– Service is not provided frequently enough
+ Positive interactions with provider/agency	– Lack of recognition of problem by provider
+ Coordinated services	– Lack of including caregiver in decisions to stop or change service
+ Good communication	– Lack of linguistically competent staff
+ Involvement of caregivers in identifying needs, planning and delivering services	

Of thirty families in the study, seven African American and eight Hispanic families participated. Their experiences with the helpfulness of services and supports varied depending on their ethnic/racial background, language proficiency, education, and immigration status and permanency. For Spanish-speaking families, lack of bilingual staff diminished the value and benefits of the services provided.

For most families who participated in the study, the mother was the primary care giver. However, African American and Hispanic families reported that they relied heavily on family members for help with childcare, extra income or emotional support.

"If nothing else, it gives me some sense of, if this makes sense to you, security. I know she's [psychologist] there. . . she is like the security thing to me."

"For TC to form those bonds with other people, [in this way] the therapist has been wonderful."

"We always have that open communication if we have a little problem going on or something, I alert them [provider]. I let them know what's going on before they get here and then we're able to monitor what is going on."

"The only time I was discontent was when the length of time between the therapist [visits]. . . if it could be a shorter period of time [weekly instead of monthly], so the children don't lose that confidence they have seeing them."

"Either they [OT with Independent Living] don't get in touch with me at all, somebody will call and say they can't come out, or they get the authorization so late that he only gets it [OT] for two weeks out of the month. I'm just really not happy with the service."

Among those who said they did not have family in the US, the caregiver herself was a source of support for family members abroad. The FEMHS study suggests that a holistic approach to care should include the role of extended families and their importance in identifying not only sources of support, but also sources of stress, such as the caregiver who provided support to family abroad.

Half the families in the study were in contact with a family support organization — the Federation of Families for Children's Mental Health was the organization most frequently mentioned. These families consistently reported how helpful the organizations were to them in providing information, support and opportunity to vent feelings. For many families, contact with other family members who were experiencing similar challenges gave them hope, understanding and respect, time to talk and explore options, and provided them a guide along a complex path and difficult journey to mental health services.

Many families also turned to friends, family, and spiritual connections for support and guidance. Some families often heard about services and supports through word of mouth or happenstance. For example, one family found out about a therapist and the eligibility requirements of the program from another parent while she was in the waiting room of a mental health center waiting for her child. Another mother found out about a service from another parent while they were at the playground with their children. These findings underscore the important roles family and advocacy organizations and informal supports play in a family's opportunity to learn about mental health services and feel supported in the process.

What the Research Says

For years, the behavioral and physical health literature has identified practitioner qualities and traits that patients see as important (Dinnebeil & Rule, 1994). For example, Darragh and associates (2001) identified three themes when interviewing 51 participants with brain injury:

- 1) Roles of the provider and their willingness to don a variety of roles (e.g., friend, mentor, team member, advocate);
- 2) Perceived helpfulness of services including relevance, meaningfulness, practical application, skill development and whether periodic feedback on progress was given; and,
- 3) Personal characteristics of the providers, including being a clear and honest communicator, supportive, respectful, good listener, and understanding.

Worthington and associates (2001) reviewed several studies and found several of the same qualities perceived by caregivers as helpful in mental health providers — knowledge in the field; good

I don't think he'll (brother) let me lose the house, you know. I know he'll give me some money."

communication skills, both listening and responding; a family centered approach; supportiveness to families; positive personality traits; positive outlook; sensitivity; sharing information and building parent's confidence; and, clarifying team members' expectations. The literature also validates the importance and relevance of a parent's view about the helpfulness of a provider, their services and the treatment they provide (Tarico et al., 1989).

Studies have found informal helpers to be major sources of support, even though some support is inconsistently provided due to limitations of emotional, financial and physical resources of family, friends and community supports (Lazear & Worthington, 2002). Increasingly, research supports the helpfulness of the types of services and supports that informal helpers can provide. For example, findings from studies looking at respite services found respite did help families who received it (Burns & Burchard, 2000), and helped to sustain family stability, avoid out-of-home placements, and reduce the likelihood of abuse and neglect (ARCH National Respite Network and Resource Center, 2002).

Research also validates the perspective of the parents and caregivers in the study who identified extended supports provided to the whole family as helpful. For example, Dellve and associates (2000) examined the coping processes of siblings whose brother or sister had an emotional or behavioral challenge. Their findings lead to the conclusion that a better understanding by siblings of their brothers' or sisters' disability is associated with more empathetic attitudes. Thus, they concluded, it is important that siblings' voices be included in the design and delivery of services.

A growing body of literature supports the critical role family organizations play in providing peer support to other families (Clausen et al., 1998; Bryant-Comstock et al., 1996; Koroloff et al., 1996) and ensuring families have access to needed quality services (Anderson et al., 2002; Kamradt, 2000; Nash et al., 1992; Worthington, et al., 2001).

Studies are assessing the public's recognition of emotional and behavioral disorders and their beliefs about the effectiveness of various treatments. Jorm and associates (1997) refer to this public recognition as "mental health literacy." Their research concludes that, "If mental disorders are to be recognized early in the community and appropriate intervention sought, the level of mental health literacy needs to be raised. Further, public understanding of psychiatric treatments can be considerably improved" (pg.1).

As more formal and informal helpers are being called upon to identify and provide supports and services to youth with emotional or behavioral challenges and their families, greater attention must be paid to broadening the mental health knowledge base of the community. Stiffman and associates (2000) found that professionals

who come into contact with youth (e.g., physicians, social workers, teachers, police officers, etc.) are most likely to refer youth for mental health services when they feel capable of making a mental health assessment of the child and when they are familiar with the mental health services available in the community for that child.

System of Care Checklist: Helpfulness of Formal Organizations and Informal Supports

Service can be more helpful to families if...

- ☐ The family is treated with respect and is seen as the lead in planning services for their child.
- ☐ The family is given all the information necessary to partner in treatment decisions and make decisions from a position of strength.
- ☐ Services are coordinated across providers.
- ☐ Communication among providers and between families and providers is effective and efficient.
- ☐ Families receive accurate information about what services offer and the eligibility criteria to receive those services.
- ☐ There is a positive relationship between the service provider and the child and between the parent and the service provider.
- ☐ Families feel confident in the skills of their child's service provider and have information available to them about the skills and experiences of specific providers.
- ☐ The service provider is accessible and responsive to the requests and needs of caregivers.
- ☐ Supports and services (i.e., mentors, sibling counseling, respite) are extended to the whole family.
- ☐ The care manager works in partnership with the family to examine all life domains and how to support each, as necessary (e.g., transportation, food, housing).
- ☐ Families receive regular contact from providers about their child's progress.
- ☐ Families do not have to wait an unreasonable amount of time for an appointment or sit in the waiting room an unreasonable amount of time for a scheduled appointment.
- ☐ Therapist, care managers or other direct service personnel remain relatively constant while the child is in service.
- ☐ Families feel that the service addresses the need.
- ☐ All aspects of service provision are conducted in a culturally competent manner, including meetings with the family about the youth, or his or her services and treatment (e.g., conducted in the primary language of the caregiver).
- ☐ The approach to care is holistic and family-centered, and includes examining the role of extended family as a source of support as well as a source of stress.

- ☐ Families are aware of and have access to family advocacy and support organizations in their community.
- ☐ Families and treatment team members are clear about their roles and tasks.
- ☐ Agencies and service providers are flexible to meet the needs of the family, such as time of appointments and locations.
- ☐ Policies are in place whose main objectives are to raise the mental health literacy of the community.

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Family Experience of the Mental Health System

of Child & Family Studies, Louis de la Parte Florida Mental Health Institute (FMHI), at The University of South Florida (USF), Tampa, funded by the U.S. Department of Health and Human Services, Center for Mental Health Services, and the National Institute on Disability and Rehabilitation Research from September 1999 – August 2004. The RTC's mission is to increase the effectiveness of services systems for children and youth with emotional disturbances and their families by strengthening the empirical base for such systems.

The Family Experience of the Mental Health System study has had guidance and invaluable input during the course of the study from parents, and other primary caregivers, and youth. A Family Advisory Committee met each year (2000–2003) at the Federation of Families for Children's Mental Health Annual Conference to help refine research questions, develop protocol, discuss preliminary findings, and examine dissemination strategies. We gratefully acknowledge their insight and guidance.

This study is based on interview data collected over two years from thirty families throughout Hillsborough County, Florida. In the face of continuing challenges and uncertainty, these families allowed us into their homes and shared their stories, with great insight, sometimes anger and sadness, and often with humor. They have our gratitude and respect.

The Family Experience of the Mental Health System (FEMHS)

is one of seven major studies at The Research and Training Center (RTC) for Children's Mental Health, Department

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The RTC's mission is to increase the effectiveness of services systems for children and youth with emotional disturbances and their families by strengthening the empirical base for such systems.



Research & Training Center
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Louis de la Parte
Florida Mental Health Institute

Family Experience of the Mental Health System (FEMHS)

(FMHI Series Publication #224)

This publication is also available on-line as an Adobe Acrobat PDF file:

<http://rtckids.fmhi.usf.edu/rtcpubs/familyexperience.htm> or <http://pubs.fmhi.usf.edu>

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