Overview

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Family Experience
of the
Mental Health System

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.

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[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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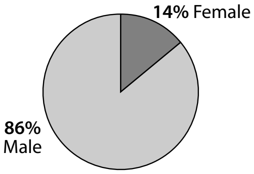
The Findings Compendium provides information in a series of user-friendly "Findings Briefs" and offers specific "checklists" to summarize findings and their policy and practice implications. The Findings Compendium, also available as a downloadable publication or cd-rom, emphasizes the importance of 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.

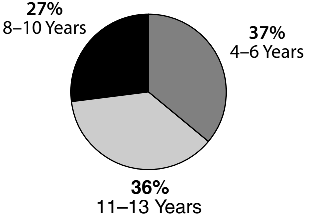
The thirty families who participated in the study were in the early stages of their search for services for their children. The majority of the children were male (86%), ranging in age from 8 to 13 years old. Fifty percent of the families described themselves as Caucasian, 27% Latino, and 23% African 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

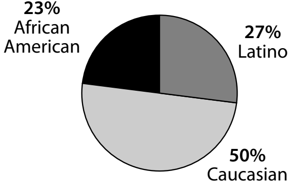
Child's Gender



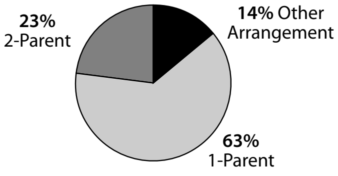
Child's Age



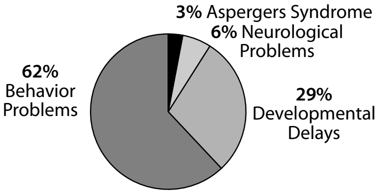
Child's Ethnicity



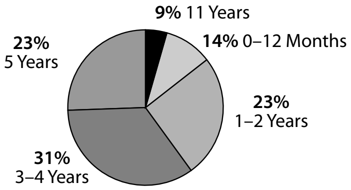
Caregiver Status



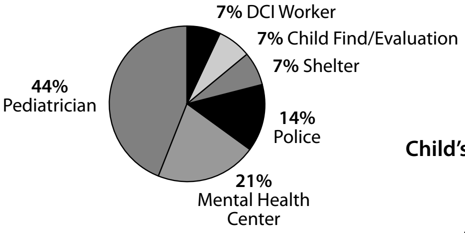
Reasons for Seeking Service



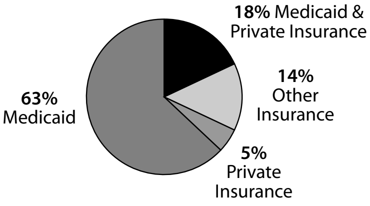
Age of Child When Problem First Noticed



First Person Talked to About Services



Child's Health Care Coverage



Findings Brief 1 Methodology and Attributes

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

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

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

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

" 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."

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 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.

"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?"

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.

"They keep connecting you to other places and send you other places"

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

Finding 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).

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

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.

"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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