Findings Brief 1

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Family Experience of the Mental Health System

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.

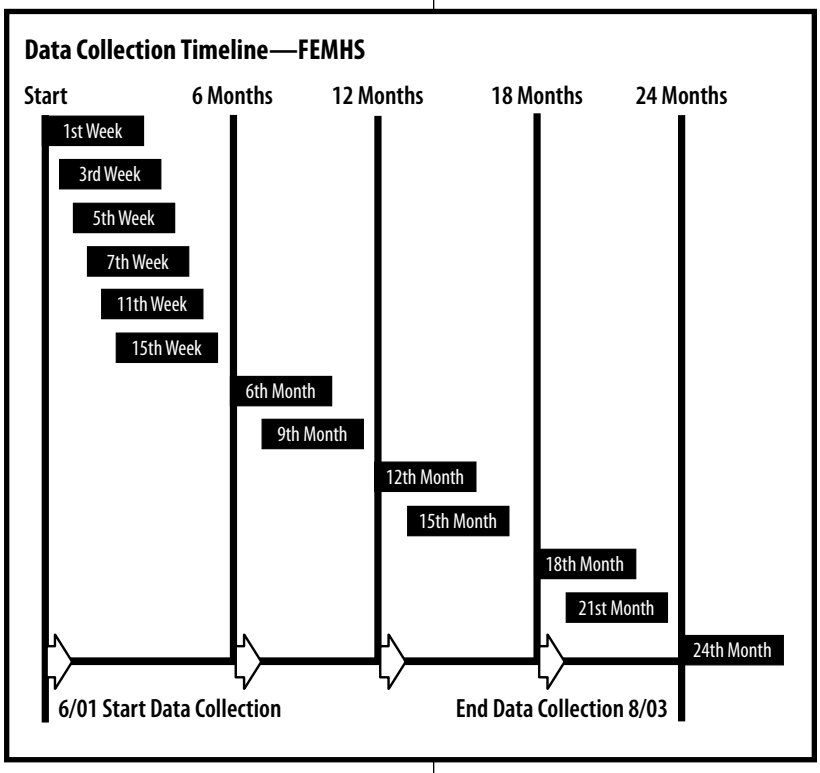
Seeking to understand, rather than predict or generalize. . .

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.

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.

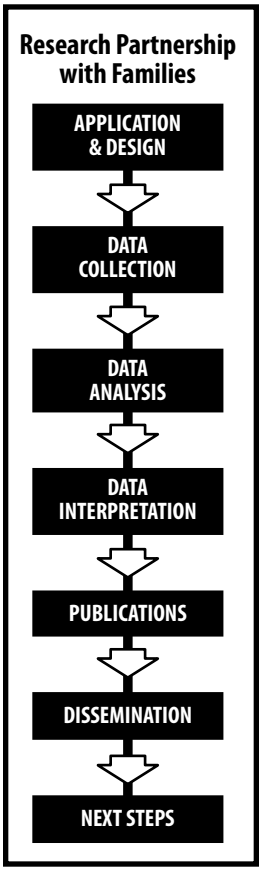
In order to preserve the richness and context of the interview data and increase the validity, reliability and objectivity of the findings, the data were organized and analyzed by a variety of methods, including the use of manual techniques and N-VIVO computer software, a qualitative software program 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 Medidate 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 Zanex; 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,

References

Findings Brief 1 Methodology and Attributes

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