



# EVALBRIEF: SYSTEMS OF CARE

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## Family Involvement in Systems of Care: Findings From the Family-Driven Study

### Introduction

As part of the national evaluation of systems of care, a team led by parents and supported by researchers came together to study the experiences of families in systems of care. The study was jointly conducted by the Federation of Families for Children's Mental Health and the Georgia Parent Support Network. The team consisted of five culturally and geographically diverse family members and several researchers. They identified three goals that provided a framework for their work: (1) to identify research questions that would be of interest to family members and align with family values; (2) to have family members take the lead in designing and directing the study; and (3) to record the history, process, and experience in order to understand and document the team's journey.

To help focus the broad research goal of better understanding children's and families' experiences with systems of care, the team conducted a modified Delphi process, a technique to build consensus employing a series of written questionnaires with cycles of feedback rather than face-to-face discussion. The team first identified 100 family members, youth, and professionals with expertise in different aspects of children's mental health. These experts received three waves of questionnaires. The first wave generated a wide range of topics that could be studied; the second and third waves helped narrow the topics and, through a ranking exercise, resulted in priority questions of interest. Based on results from this process, the team selected three research questions

### Study Highlights

- ▶ ***Families reported being engaged in systems of care principally through participation in their child's treatment.***
- ▶ ***Respondents indicated that lack of access to services and funding were the greatest barriers to family engagement.***
- ▶ ***Families attributed greater levels of family support and increased empowerment to their engagement in systems of care.***

to examine family members' perspectives on their engagement with systems of care:

- ▶ How are families engaged in systems of care?
- ▶ What supports or inhibits family engagement in systems of care?
- ▶ Is there a relationship between family engagement and child and family outcomes?

The focus of this *EvalBrief* is on the first two research questions. A future *EvalBrief* will address the third research question.

## Methods

Participants from three system of care communities (Jackson, Mississippi; Indianapolis, Indiana; Willmar and Olivia, Minnesota) whose children were enrolled in the national evaluation and who had received services in the prior 12 months were invited to respond to a brief self-administered survey questionnaire. The questionnaire consisted of both closed-ended questions with Likert-type response options and open-ended questions asking participants to provide additional descriptive information. The closed-ended questions addressed ways the family was engaged in systems of care and the degree to which they felt involved. The open-ended questions explored what supported or inhibited their engagement.

Respondents were asked how they felt their engagement had led to a change in their child or family, what aspects of their engagement had contributed to the change, and what barriers hindered their ability to engage. The survey response rates, based on family members who agreed to be contacted to participate in the study, were 68.2% (Mississippi), 71.1% (Indiana), and 70.7% (Minnesota).

Survey respondents also were invited to participate in focus groups to further explore their opinions, attitudes, beliefs, and perspectives on family engagement in systems of care. A total of five focus groups (with seven to nine participants each) were conducted across the three communities.

The findings presented in this brief are a synthesis of answers to the open-ended survey questions and questions posed in the focus group discussions. Team members, working in pairs, conducted thematic coding of these qualitative data, looking for patterns, similarities, and differences.

Starting with the survey data, each pair reviewed a printout of all the open-ended responses to one question. Separately, each member of the pair

identified themes that emerged from the data and then compared their results to develop a common language about the themes. In a similar manner, each pair reviewed one of the focus group transcripts to identify themes in the discussion. Together, the team reviewed all the themes that emerged from these reviews and decided on a set of overarching categories so there would be consistency across the final analyses.

Once this was done, the pairs reassigned each open-ended survey response to one (or more) of the overarching categories. In a similar manner, each pair reviewed their focus group transcript again to assign the themes identified in the discussion to these overarching categories. Findings are presented below.

## Findings

Family members who completed the survey most often said that families were engaged in their system of care through participation in their child's treatment. Lack of access to services and funding were most often cited as explanations to barriers to

### **Significant change in their child or family since becoming engaged:**

"I've gotten a lot of help to change things in my life."

"I have become stronger mentally and emotionally."

family engagement. When asked about outcomes that families attribute to their engagement, responses centered around themes of increased levels of family support, improved care and services, better access to services, and a feeling of empowerment. That is, families felt that they had

acquired the skills, knowledge, and courage to use their own voice effectively to advocate for their child and family. Family members also noted important ways their child or family had changed. Themes focused on empowerment, personal growth, self-awareness, and improvement in their child's behavior or functioning. The most common reasons given for the positive changes in the child or family were empowerment and participation in services.

Focus group findings confirmed what had been identified as key themes about family engagement in the survey data. In addition, the results provided a better context for understanding how families were engaged and identifying those factors that supported or inhibited their engagement. In terms of how they were engaged, focus group participants cited being included in their child's treatment, being involved with family organization activities, and taking an active role in team meetings. Similar to the survey respondents, focus group participants indicated lack of access to services and funding as the greatest barriers to family engagement. They also were asked to identify outcomes that they thought resulted from their engagement. The top three identified were increased empowerment, improved care and services, and better child and family outcomes.

### What inhibits a family's involvement?

"Meetings are too far away to attend."

"Work schedule and lack of child care."

After thematic analysis was completed for the open-ended survey and focus group data separately, team members conducted an additional analysis, combining themes from both data sources to better understand family engagement, what inhibits family engagement, and outcomes that families attribute to engagement. Results of this analysis, ranked to show the top five most frequently cited responses for each category, are given in Table 1.

## Summary

The family-driven research team identified three goals for this study. Each study goal was successfully accomplished, resulting in a genuine family-driven study initiative. The team was able to identify key questions of interest to families that yielded important findings, family members took the lead in directing the study and conducting the analysis, and the history and process of how the

**Table 1**  
**Most Frequently Cited Family Engagement Themes**

Rank	Most Frequently Cited Ways Families Are Engaged	Most Frequently Cited Barriers to Engagement	Most Frequently Cited Outcomes Families Attribute to Engagement
1	Participation in treatment	Lack of access to services and funding	Greater levels of family support
2	Family organization activities	Inadequate or inaccurate information	Increased empowerment
3	Team meetings	Poor communication	Improved care and services
4	Involvement with providers	Lack of support services	Improved child or family outcomes
5	Social activities	Poor relationships	Improved access to services

team and study evolved over time epitomizes a paradigm shift from families serving as subjects of research to a broader role as researchers in systems of care.

The findings from these analyses indicate that families of children enrolled in systems of care believe that their engagement has had a positive impact on outcomes. The ways families engage in systems of care and the outcomes families attribute to their engagement warrant continued research efforts in this area. This includes further study of the questionnaire itself to determine its usefulness as a means of describing engagement and how families feel about the impact of their own involvement on their child's care. The themes from the qualitative analysis suggest topics for further investigations into factors that support and those that inhibit family engagement in their child's care.

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