




The Family-Driven Study

## First Findings February 2006

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## Background

- Funded by SAMHSA - a special study of the National Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program.
- A collaboration of:
  - the Federation of Families for Children's Mental Health
  - the Georgia Parent Support Network
  - ORC Macro

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## The Three Goals of the Study

- To study a question of interest to families in a manner that was rigorous and simultaneously consistent with the family values of systems of care.
- To support families to take the lead in all aspects of designing and conducting a study with highly qualified researchers playing a supportive role and providing technical assistance.
- Document the experience, process and lessons learned from making the paradigm shift to doing research in this manner.

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## Research Questions

- 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?

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## Definition of Engagement

- Engagement is the act of doing something for your child, your self, or your family, that
  - determines or derives from a care plan or
  - supports the delivery of services and supports.
- Engagement is also participation of families and youth in governance, management or evaluation activities with the intention of improving or enhancing service planning and delivery of treatment, services, supports, or care for children in the community as a whole.
- Families may engage in different ways and intensity as their child's and family's needs change or as opportunities to become engaged in their child's care or in the system vary.

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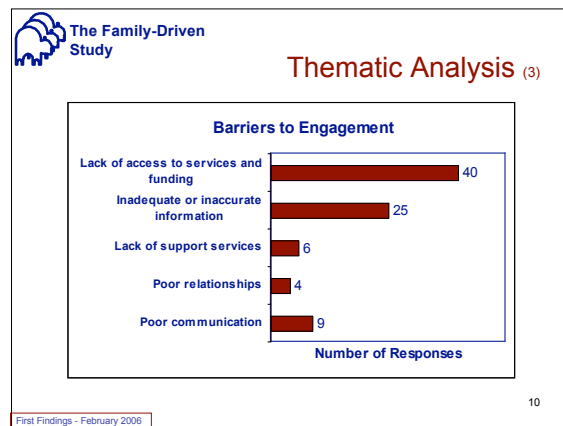
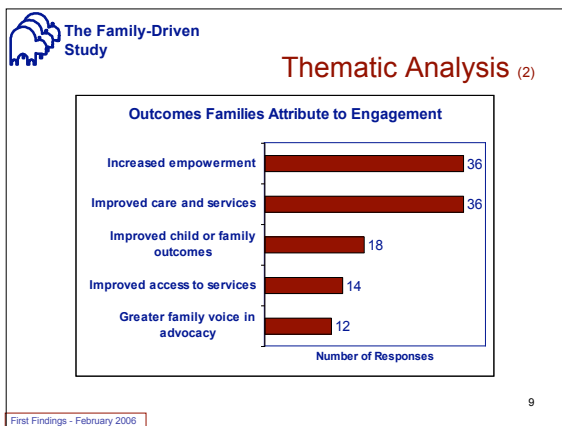
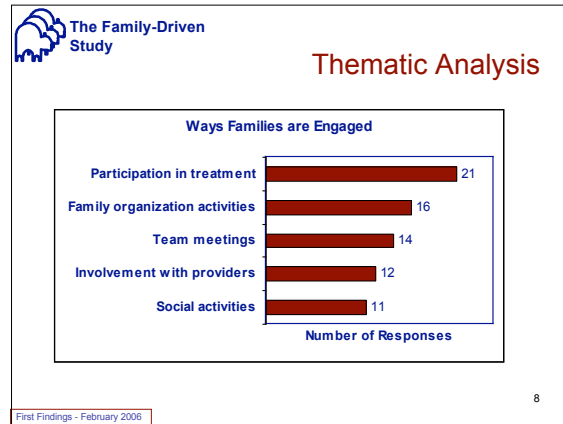
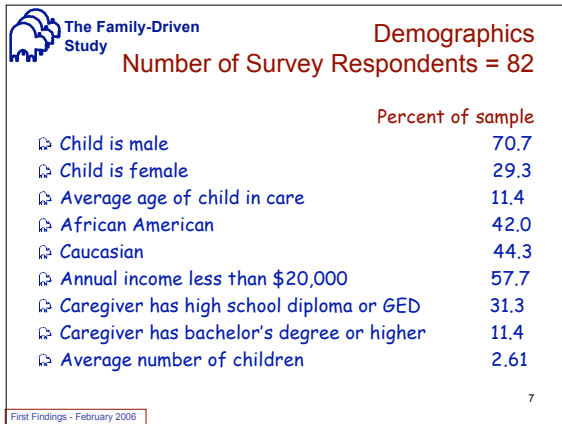
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## Methods

- Mixed method data collection
  - self-administered mail survey,
  - focus groups, and
  - data from the longitudinal study
- 3 Communities participated in the focus groups
  - Jackson, Mississippi
  - Indianapolis, Indiana
  - Willmar & Olivia, Minnesota
- Validity
  - Factor analysis reveals that questions 4a - 4d converged into one factor which we believe to be engagement.
  - Questions 4f - 4h converged into a second factor which looked at the perception of family member's outcomes as a result of their engagement.
  - Satisfying finding because study team's intent was to capture data on two different ideas related to engagement.

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### Relationship of Engagement to Outcomes

- Various analysis strategies were applied to discern relationships between the family's level of engagement and child's outcomes
  - General linear modeling to examine the change in continuous outcome variables over time as a result of engagement
  - Log linear modeling was used to investigate change in categorical outcome variables as a result of engagement
- Results generally show no significant differences between our high and low engagement groups in terms of change in their child's clinical and most functional outcomes as measured by the national evaluation.

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### Relationship of Engagement to Outcomes (2)

- In a few instances we did find some indication that there was an association between engagement groups and the following functional outcomes.
  - Expulsion from school
  - Detention in school

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## Relationship of Engagement to Outcomes (3)

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## Limitations

- ↳ The sample size was insufficient to make generalizable conclusion.
- ↳ Survey participants were not a random sample .
- ↳ Difference between levels of engagement of our participants may not have been strong enough to make a difference.
- ↳ Our instrument was not designed to measure engagement - we sought only the respondent's perception of their level of engagement.
- ↳ Survey data collection was not synchronized with the periodic 6-month data collections of the national evaluation.
- ↳ The family engagement data were not collected longitudinally.

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## Conclusions

- ↳ Families of children enrolled in systems of care believe that their own engagement in those systems of care does have an impact on outcomes.
- ↳ Families most frequently engage by:
  - ↳ participating in treatment,
  - ↳ being an active member of their child's treatment planning team, and
  - ↳ participating in family-run organization activities.
- ↳ Family engagement is nurtured by:
  - ↳ availability of support services,
  - ↳ positive relationships with peers and professionals, and
  - ↳ activities that enhance family member's knowledge and skills so they can be effective advocates for their child.

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## Conclusions (2)

- ↳ Outcomes families value and attribute to their engagement with the system of care are not typically assessed by systems of care or the national evaluation. The top themes were:
  - ↳ Increased empowerment
  - ↳ Improvements in care and services
  - ↳ Increased family voice in advocacy
  - ↳ Greater levels of family support

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## Food for Thought

- ↳ What drives family engagement?
- ↳ Why do families disengage?
- ↳ When is less family engagement a sign of success?

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