Building Research Capacity through Family-Led Community Participatory Research

Presenter:
Denetra McBride, J.D.
FAVOR, INC.
Director of Family Engagement Programming
LEARNING OBJECTIVES

• Learn how evaluation efforts can be a powerful driver for organizing the family voice to bring about systems change.

• Describe the process of conducting the family-led community participatory research from the family organization’s point of view.

• Present data from the community conversation process and illustrate the community conversation coding process.
FAVOR, Inc.

- 29 staff provide direct service family peer support and family/caregiver leadership trainings statewide.
- 96% of our staff have lived experience as caregivers of a child or other family member with mental or behavioral health challenges.
- Family System Managers work at the system level to help caregivers and youths become active and equal partners in Connecticut’s Network of Care.
Families as Full Partners

Ladder of Family Participation

- Family-initiated, shared decisions with organizations
- Family-initiated and directed
- Agency-initiated, shared decisions with families
- Families consulted and informed
- Families assigned but informed
- Families consulted as tokens
- Families used as decoration
- Families manipulated


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2014 COMMUNITY CONVERSATIONS

• After the Sandy Hook tragedy in Newtown, the Connecticut General Assembly passed PA 13-178 which directed the Department of Children and Families to produce a Children’s Mental Health Plan.

• FAVOR Family Systems Managers were enlisted to co-facilitate some of the meetings and facilitated discussions that informed the development of this plan.

• This work led to community conversations across the state which gathered input from family members and youths in a systematic way.

• 22 additional community conversations, involving 297 adults and 86 youths across the state were conducted.
COMMUNITY-BASED PARTICIPATORY RESEARCH

• Community-based participatory research (CBPR) approach allows family and youth involvement in systems change (Craig, 2008).

• CBPR, emphasizes equitable partnership with community members in all facets of research (Jazquez, Vaughn & Wagner, 2013).

• CBPR provides a robust method of collecting information regarding family and youth perceptions of a system of care.
THE IMPACT OF THE FAMILY-LED CBPR PROCESS

- Family Systems Managers gathered and analyzed data that in many ways became the blueprint of the Children’s Mental Health Plan for the State of Connecticut.

- System of care values have started to penetrate more deeply.

- Families want, and expect to be, part of the process and want to be kept abreast of the work and any progress.

- We replicated this CBPR process in 2016-2017 and 2017-2018 so that the family and youth voice continues to guide the development of the Connecticut Network of Care.
THREE KEY QUESTIONS

• What are the strengths of Connecticut’s service system for children and families?

• What are the major areas of concern within Connecticut’s service system for children and families?

• How should we fix these problems? What are your suggestions to improve our system of care?
Table A. Number of Community Conversations and Participants 2017

<table>
<thead>
<tr>
<th>DCF Region</th>
<th>Number of Conversations</th>
<th>Number of Participants</th>
<th>Total</th>
<th>Adults</th>
<th>Youths</th>
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<tbody>
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<td>6</td>
<td>5</td>
<td>66</td>
<td>25</td>
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<tr>
<td>Statewide</td>
<td>2</td>
<td>70</td>
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</table>

30 Community Conversations:
- 2 Statewide conversations
- 5 Youth conversations
- 5 Spanish-speaking conversations
DATA COLLECTION

• Family Systems Managers were trained to conduct the Community Conversations based on established methods for conducting focus groups.

• FSMs identified family champions, who assisted them by taking notes on flip charts that summarized the main points for the group.

• Network of Care Managers from Beacon Health Options used a note-taking template to record the most salient aspects of the conversations.

• Notes from the flip charts and note-taking template were synthesized and coded for analysis.
<table>
<thead>
<tr>
<th>Service Characteristics – SER</th>
<th>Family Support – FS</th>
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</thead>
<tbody>
<tr>
<td>Access to service – SER_ACCESS (+/-)</td>
<td>Caregiver support – FS_Caregiver (+/-)</td>
</tr>
<tr>
<td>Agency policies – SER_POLICY (+/-)</td>
<td>Youth support – FS_Youth (+/-)</td>
</tr>
<tr>
<td>Communication With Families – SER_COMMUN (+/-)</td>
<td>Recreational – FS_REC (+/-)</td>
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<td>Individualized – SER_INDIV (+/-)</td>
<td>Basic Needs – FS_NEEDS (+/-)</td>
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<td>Strength-based – SER_STREN (+/-)</td>
<td>Caregiver Training – FS (+/-)</td>
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<td>Quality of Service – SER_QSERVICE (+/-)</td>
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<td>Quality of Staff – SER_QSTAFF (+/-)</td>
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<td>Professional Development – SER_PROFDEV (+/-)</td>
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<tr>
<td>Respect – SER_RESPECT (+/-)</td>
<td>System Characteristics – SYS</td>
</tr>
<tr>
<td>Service Culture – SER_CULT (+/-)</td>
<td>Family Voice – SYS_VOICE (+/-)</td>
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<td><strong>Schools – SCH</strong></td>
<td><strong>Schools – SCH</strong></td>
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<td>Family Choice – SYS_CHOICE (+/-)</td>
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<td>School Climate – SCH_climate (+/-)</td>
<td>Insurance – SYS_INSURE (+/-)</td>
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<td>Professional development – SCH_ProfDev (+/-)</td>
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<tr>
<td>School Culture – SCH_CULT (+/-)</td>
<td>Professional Development – SYS_PROFDEV (+/-)</td>
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<tr>
<td>Quality of School Staff – SCH_QStaff (+/-)</td>
<td>Policies – SYS_POLICY (+/-)</td>
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<table>
<thead>
<tr>
<th>Community Characteristics – COMM</th>
<th>System Culture – SYS_CULT (+/-)</th>
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</thead>
<tbody>
<tr>
<td>Community Resources – COMM_RESOURCE (+/-)</td>
<td>System Gaps – SYS_GAPS (+/-)</td>
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</table>

**Notes**: The table shows the relationship between service characteristics and family support, categorized by different aspects of service delivery and family engagement. Each service characteristic is paired with a corresponding family support measure, indicating areas where support is provided or needs improvement. The table also categorizes these interactions into different domains such as schools, community characteristics, and system information, each represented by different codes (e.g., SCH, COMM, SYS). This structure helps in identifying gaps and areas for improvement in both service delivery and family support.
What is working?
I have a good psychologist that is only 25 min away and she has been great.
SER_ACCESS+, SER_QSTAFF+

What is not working?
Resources are not updated, or are out of date and not correct.
SYS_INFO-

Recommendations
The systems need to communicate and all be on the same page for better access.
SYS_GAPS
DATA ANALYSIS & DISSEMINATION OF FINDINGS

• The Family Systems Managers were trained in basic content analysis (Krueger, 1994).

• Guided by the Evaluator, the Family Systems Managers analyzed the data and developed lists of strengths, areas for growth and recommendations for improving the system of care.

• Continued participation in work groups to ensure that the voices and desires of the community members are heard.

• FAVOR worked with the evaluator on the content analysis of the data and brought the results back to our communities.
STRENGTHS OF THE NETWORK OF CARE

• Families report increased opportunities to share concerns and ideas regarding the behavioral health system.

• Trainings are highly valued and encourage families to seek out opportunities to contribute to the network of care.

• Peer-to-peer support is effective, authentic and valued.

• Relationships with the Department of Children and Families have significantly improved.

• Families report high levels of satisfaction with care coordination services.

• School staff is viewed as well-trained and provide needed supports to students with mental health needs.
RESOURCES NEEDED

• Transitions between levels of care and service providers can be problematic. Families and youth suggest transition planning begin early.

• Additional staff who are fluent in the languages spoken by families seeking services.

• Additional peer-to-peer support for caregivers newly accessing the service array and peer-to-peer support for foster families.

• Transportation to services throughout the state.

• Improved engagement of families by schools through respectful and effective communication. Funding cuts have significantly impacted school services.
RESOURCES NEEDED cont.

• There is a need to develop a more stable workforce and decrease staff turnover that can be detrimental to families.

• Additional treatment and supports for children and youth on the autism spectrum and their families.

• Families value EMPS services but feel that workers prioritize completing paperwork over diffusing the crisis. Restructuring the schedule to allow for completion of paperwork after the crisis is diffused.

• Information about services remains difficult for families to utilize and navigate.
STRUCTURES THAT NEED IMPROVEMENT

• Families need to be full partners at all decision-making tables and meeting times need to be flexible to accommodate families to have an effective network of care.

• Increased accountability throughout the system including child welfare, education, and behavioral health providers with a focus on improved communication.

• Continue participation in work groups to ensure that the voices and desires of the community members are included in the plan.

• FAVOR worked with the evaluator on the content analysis of the data and bringing the results back to our communities.
PROFESSIONAL DEVELOPMENT

- Community Resources such as sports and after-school programs provide important supports for youth.
- There is a need for the development of structures to engage in peer-to-peer support to enhance their natural supports.
- The State Department of Education should implement a system-level approach regarding bullying.
- Increased training for clinicians, DCF staff, first responders, providers, parents and caregivers and psychiatrists.
YOUTH VOICE

• Juvenile Review Boards have led to significant improvements in how the system responds to youth.

• Community Resources such as sports and after-school programs provide important supports for youth.

• There is a need for the development of structures to engage in peer-to-peer support to enhance their natural supports for youth.

• The State Department of Education should implement a system-level approach regarding bullying.
YOUTH VOICE cont.

• The process to screen foster parents needs improvement. Youth request increased accountability and mechanisms to file grievances without fear of repercussions.

• Requests that youth in foster care have a voice in decisions that directly affect them:
  • Placement decisions
  • Appointments with DCF workers and medical providers without foster parents present.
  • Workers prioritize building a trusting and supportive relationships with open communication.
### 2017/2018 COMMUNITY CONVERSATIONS

#### Table A. Number of Community Conversations and Participants

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of Conversations</th>
<th>Total</th>
<th>Adults</th>
<th>Youths</th>
</tr>
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<tbody>
<tr>
<td>TOTAL</td>
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33 Community Conversations:
- 8 Youth conversations
- 4 Spanish-speaking conversations