Behavioral Health is Essential To Health

Prevention Works

Treatment is Effective

People Recover
The Importance of Family Involvement in Evaluation

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As We Create Evaluation Teams...

“If citizens are to participate in the development of policy decisions that affect their own lives, the standard practitioner-client model must give way to a more democratic relationship between them.”

-Frank Fisher
Why Engage Families?

• Families provide an authentic measure regarding the effectiveness of services and supports
• Family engagement increases the credibility of the evaluation outcomes
• Families are strong advocates for initiatives that are proven to be effective
Why Engage Families (cont.)

- As families become knowledgeable of evaluation outcomes, they become stronger partners in systems change
  
  ➢ Systems don’t change, people change systems

- Family engagement demonstrates the system’s commitment to the mantra
  
  ➢ Not About Us Without Us
The Role of the Family In the Evaluation Process

• To define “success”
• To identify outcomes that are important
• To help develop tools and processes that reflect the norms of the community
• To engage other families to participate
• To affirm that we are headed in the right direction
• To help to analyze the results
Why Parents Are Hesitant to Participate

- Feelings of blame and disrespect
- Feelings of isolation due to lack of information
- Feelings of intimidation
- Feelings of being outnumbered
- Feelings of incompetence due to not knowing the jargon
Why Professional Are Hesitant to Engage Families

• Concerns about confidentiality
• Lack of understanding about the unique expertise that families bring to the process
• Issues of cultural clash
• Issues of mistrust
• Issues of power
Creating Family-Driven Evaluation Processes Can Be Challenging

Thoughtfully consider the following when designing your evaluation team......
Considerations

• Often, evaluators are not intimate members of the community they are evaluating
• Evaluators may lack a full understanding and/or appreciation of the dynamics of the community
• Concomitantly.....family members may not have a full understanding and/or appreciation of the evaluation process or the constraints upon the evaluator
Considerations

• Evaluation is not typically considered a component of the continuum of services and supports for children and their families.

• It’s not clear that anyone (professional or family) considers evaluation to impact the family in the same way that traditional services and supports do.
Engagement Tips

• Ensure maximum *cultural humility* throughout the process; be inclusive of families of diverse cultures, ethnicities, religions, and lifestyles

• Create open, transparent dialogue and balanced, respectful relationships

• Foster an understanding that a dynamic evaluation process can be very beneficial in the continued improvement of services and supports for the child and the family
Additionally...

Because the evaluation process is tied to Federally-mandated requirements, we often lapse into a very strange and unfamiliar language:

• Create an easy to understand lexicon for all team members

• To the greatest extent possible, utilize “kitchen table” terminology
How Do We Measure Authentic Engagement?

• **Authentic engagement** defies quantitative measurement; it’s like trying to measure “love”
• Create benchmarks to determine that families are valued contributors to the evaluation process
• Create roles for families in *every aspect of the evaluation process*
• Ask identical questions to all team members (e.g. Are families truly engaged, How engaged do you feel you are in the process)
Ana Maria Brannan, PhD
Involving Families in Evaluation

• The shift from family-blaming to family-focused to family-driven requires meaningful family member involvement in:
  - Policy decision-making
  - Shaping of service system
  - Direct service delivery

• Traditionally, family members were relegated to being mere providers of information
Involving Families in Evaluation

Meaningful involvement in all of these activities requires family members to:

• Have solid understanding of what is already known (i.e., consumer of research literature)

• Determine what information is needed to inform decisions

• Shape procedures for recruitment of participants and collection of data

• Help interpret what findings mean and how the information should be used
Involving Families in Evaluation

- Family members offer unique knowledge and skills needed for evaluation efforts to be ecologically valid.
- The challenge is how best to conduct evaluation efforts in order to maximize family member contributions.
Involving Families in Evaluation

• SAMHSA’s system of care initiative promoted roles for families in evaluation
• This role began to expand considerably in the mid to late 1990s
• Involvement has continued to evolve over time
Types of Activities

• In a survey of 37 grantee sites* several areas of evaluation involvement in federally-funded SOCs were identified:
  – Modification of data collection instruments
  – Data collection
  – Reviewing results
• They found low involvement in:
  – Hiring evaluation staff
  – Processing data

*Osher, et al. (2001)
Benefits

• Findings from focus groups indicated that family participation in evaluation was perceived as:
  – Improving the quality of the data collected
  – Potentially leading to improved outcomes for children and families

• Research is needed to test whether these perception bear out empirically

-Osher, et al. (2001)
Participatory Approaches

- Community participatory research (CPR) has gained prominence in recent decades
  - Rooted in social justice
  - Emphasizes change and reform
- In SOC evaluation, family involvement does not always follow CPR key practices*
  - National evaluation relies heavily on input from family representatives but is not truly CPR
  - Local evaluation efforts have greater opportunities for true CPR

*Pullmann, 2009
Participatory Approaches

Community participatory research involves:

• Fair representation of all perspectives
• Increased awareness of the others’ views
• Increased awareness of others’ motivations and values
• Understanding that the goal of evaluation efforts is to promote/inform change
• Redistribution of power that benefits all participants
Challenges

Efforts to involve family members in evaluation often fall short

• Involvement is not always authentic
• Family members may perceive their involvement differently than professionals
• Family members may feel exploited
• Family members often serve in roles with little decision-making power

Sources: Jivanjee & Robinson, 2007; Osher, et al., 2001; Pullmann, 2009
Challenges

Researchers may be reluctant to involve families

- Family members and evaluators “speak different languages”
- Evaluators may not have background in participatory approaches
- Concerns about confidentiality
- Concerns about compromising “rigor”
Some communities resist being involved in evaluation

- History of abuse by researchers
- Potential conflict between the role of advocacy and “objective” evaluation
- View the goals of evaluation differently
Recommendations

- Pullmann (2009) asserts that meaningful family member involvement is impeded by the power differential
  - Recommends an approach that is authentically participatory and liberatory
  - Emphasizes true collaboration that creates a “critical consciousness in the community” (p. 51)
  - Stresses the shared goal of system reform and transformation
Family Involvement in Evaluation: Connecticut Network of Care

Jeana Bracey, PhD, Tim Marshall, MSW, Joy S. Kaufman, PhD, Susan Graham, MSW
Agenda

• Context in Connecticut in 2014
• Community-based participatory research process
  – What we learned
  – How findings were shared
  – Results of this work
• Increasing access to data
  – Data Integration Workgroup
  – Connecticut Data Collaborative
  – Enhancing family skills related to data
Learning Objectives

• Participants will learn about the impact that family-led evaluation efforts can have on state policy development
• Participants will be exposed to methods to train community members to engage in evaluation
  Participants will be exposed to methods to increase family access to data
• Participants will learn about strategies for organizing family voice as a powerful driver in systems change
Family-Led Evaluation Process
Context in Connecticut in 2014

- Sandy Hook tragedy in Newtown; 12-14-2012
- Sandy Hook Commission created in January 2013
  - Tasked with developing recommendations intended to reduce the probability of another tragedy
  - Recommended that a system of care be built that goes beyond treating mental illness to foster health in individuals, families and communities and embrace overall psychological, emotional and social well-being
- PA 13-178 passed by the CT General Assembly, Dec. 2013
  - directed the Department of Children and Families to produce a children’s behavioral health plan for the state by October 2014
Development of the Children’s Behavioral Health Plan

- PA 13-178 Advisory Committee appointed to guide the planning process
- Consultant conducted a series of meetings and facilitated discussion to solicit input from consumers, families, content experts and state and local stakeholders; Family Systems Managers were asked to co-facilitate some meetings
- Expanded the reach of this work; meetings conducted across the state and to gather input from families and youth in a systematic way that would allow for analysis of the data
- 22 additional community conversations were scheduled and conducted by the Family Systems Managers
Community-Based Participatory Research

• SOC hold as a core value that the system be family-driven and youth-guided, yet achieving this in the evaluation of these systems has been difficult

• Community-based participatory research (CBPR) is an approach that holds unique promise for capitalizing on family and youth involvement in systems change*
  – emphasizes equitable partnership with community members in all facets of research**
  – provides a robust method of collecting information regarding family and youth perceptions of a system of care

*Craig, 2008; **Jazquez, Vaughn & Wagner, 2013)
Family Systems Managers developed a data collection protocol that had three primary 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?
Data Collection

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

- A note-taking template was developed and Family Systems Managers were trained to record the most salient aspects of the conversations.
Data Analysis

• These notes were shared with the CONNECT Evaluation team who coded and sorted the data for analysis

• The Family Systems Managers were trained in basic content analysis* and guided by the Evaluator, they:
  – analyzed the data
  – developed their list of strengths, areas for growth and recommendations for improving the system of care

• The Evaluator created an initial summary which was reviewed by the Family Systems Managers and revised

• 22 Community Conversations were held across the state which included 297 adults and 86 youth

*Krueger, 1994
Results:
Strengths of the Network of Care

- Advocacy Services
- Support Groups
- Non-Traditional Service Providers
- In-Home Services
- Differential Response
- Parent Education
- Department of Children and Families
- Network of Care Staff
Results – Resources Needed

- **Stigma Reduction Campaign**
- Basic Needs
- Access to Resources
- Transportation
- Peer-to-Peer Support for Youth
- Peer-to-Peer Support for Caregivers
- Parent Education

- **Training** for School Staff
- **Training** for Primary Care Providers
- **Training** for Police
- **Training** for DCF Workers
- Training for Youth
- Culturally Competent and Linguistically Appropriate Services
Results – Resources Needed

• Stable Workforce
• Network of Care Staff Training
• Trauma Informed Care
• Planning for Transitions
• Substance Abuse Treatment for Youth
• Child Psychiatry
• Childcare for Children with Social-Emotional Needs
• Recreational Services for Children with Social-Emotional Needs
• Supports for Foster Families
Results: Structures that Need Improvement/Enhancement

- Parents as Full Partners
- Time Limits on Services
- Funding Mechanisms for Non-Traditional Providers
- Interagency Collaboration
- Enhanced Communication with Foster Families
- Changes in Reimbursement Policies
- Accountability
- Infoline
Data Feedback

• Public posting of the summary including recommendations on website www.planforchildren.org

• De-identified raw data was also posted on the Website to increase transparency of the process

• Family System Managers fed the data back to each of the groups that participated in a Community Conversation
Data Feedback

• Family Systems Manager and the Evaluator presented the methods of this process and the results to the State Legislature

• These data were also presented to the PA 13-178 Advisory Committee

• The Family System Manager and Evaluator participated in a work group that was tasked with writing the behavioral health plan insuring that the voices and desires of the community members were included in the plan
Impact of this CBPR Process

- Significant impact on the Behavioral Health plan that was developed for the state and approved by the Governor and State Legislature
- Data gathered and analyzed by the Family Systems Managers in many ways became the blueprint of the Children’s Behavioral Health Plan for the State of Connecticut
- System of care values have started to penetrate more deeply
- Workgroups from CONNECT and the PA 13-178 Advisory group are working together or have become integrated
- Families want, and expect to be, part of the process and want to be kept abreast of the work and any progress
Enhancing Family Access to Data
Access to State Data

• In 2011, Governor Malloy began to require that all State departments release data to CT citizens

• CT’s open data portal was launched in 2012

• While improved, accessing data from the CT Data Portal can be difficult and the types of data are limited
Access to State Data

• In 2014 the CONNECT project became aware of the Connecticut Data Collaborative (ctdata.org)

• CT Data Collaborative is a public-private partnership that advocates for the public availability of open and accessible data to drive planning, policy, budgeting and decision-making at the state, regional and local levels

• The Data Collaborative takes data from the CT Data Portal and reformats the data to make it more accessible for community members

• CONNECT has partnered with the Data Collaborative to increase accessibility to the data via enhanced interface on the site and training for community members
Access to State Data

• While mandated by the Governor to provide data on the portal, the types of data available were at times outdated and did not answer all of families’ questions

• **Data Integration Team** was formed in 2016 with the goal of providing a forum for state departments and families to work together to decide which data to place on the portal

• Work so far has included families identifying the data they would like to see and state departments indicating what data they have available

• Within the next few months data will be added to the portal and uploaded to CTData.org
CONNECT Evaluation Team and FAVOR (state-wide family organization) collaboratively developed a **Data 101 Training**

- To increase the capacity of family members to utilize data as they sit at decision-making tables
- Interactive exercises focuses on:
  - Understanding statistical concepts
  - Being able to read charts and graphs
  - Understanding what the data is saying
  - Learning to ask questions of the data
Data in Our Everyday Life: Mean

On average, how much money do I spend on lunch each day?

<table>
<thead>
<tr>
<th>Day of the week</th>
<th>Cost of lunch</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>$4.37</td>
</tr>
<tr>
<td>Tuesday</td>
<td>$12.14</td>
</tr>
<tr>
<td>Wednesday</td>
<td>$6.89</td>
</tr>
<tr>
<td>Thursday</td>
<td>$8.34</td>
</tr>
<tr>
<td>Friday</td>
<td>$5.36</td>
</tr>
<tr>
<td>TOTAL (or SUM)</td>
<td>$37.10</td>
</tr>
</tbody>
</table>

To get the MEAN average you take the SUM and divide by the number of days you had lunch.

\[
\text{Sum} \quad = \quad \text{MEAN} \\
\frac{\text{# of items}}{\text{SUM}}
\]

Now take the SUM, and divide by the number of days.

\[
\frac{\$37.10}{5} = \$7.42
\]

\[
\bar{x} = 7.42
\]

On average, how much money do I spend on lunch each day?

$7.42
Data in Our Everyday Life: Median

The middle number (just like the median strip that divides a highway down the middle; 50/50)

The median is the exact middle number in a sequence or a set of numbers
Data Sleuth: Sample Size

Impact of Treatment XYZ (N=18)

Caucasian (n=10):
- Improve: 75%
- Stay the same: 15%
- Get worse: 10%

Latino (n=6):
- Improve: 60%
- Stay the same: 20%
- Get worse: 20%

African American (n=2):
- Improve: 0%
- Stay the same: 0%
- Get worse: 100%

Legend:
- Improve
- Stay the same
- Get worse
Next Steps for Family Involvement in Evaluation in Connecticut

- Replicating Communicating Conversations this fall so that the family and youth voice continues to guide the development of the CT Network of Care
- Training youth to collecting information from their peers regarding their perspective of the service system
- Continuing our work to enhance access to data through the Data Integration team
- Offering Data 101 trainings around the state with the goal of transitioning “ownership” of this process to our State-Wide Family Organization
Q & A

Submit your questions now

CMHIEval@westat.com

Submit your questions later
Join Us!

**CMHI National Evaluation Web Event Training Series**

The Importance and Practical Strategies for Involving Youth in Evaluation
Thursday, November 17, 2016/1-2:30 pm ET
Register Now [goo.gl/kMNZHU](http://goo.gl/kMNZHU)

Continuing the Dialogue: Engaging Youth in Evaluation
Thursday, December 8, 2016/1 - 2:00 pm ET
Register Now [goo.gl/RRWOQx](http://goo.gl/RRWOQx)