TRAINING FAMILY MEMBERS AS RESEARCHERS

The 23rd Annual Children’s Mental Health Research and Policy Conference
University of South Florida
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COMMUNITY EVALUATION TEAM (CET)

○ Families receiving System of Care Services were invited to join the Community Evaluation Team once they completed their 6-month follow-up evaluation interview

○ Families were surveyed by the Family Evaluator to determine interest in the CET and to determine the best day and time for families to participate in meetings.

FIRST CET MEETING

○ Catered by a popular restaurant

○ Offered a chance for attendees to socialize

○ Twenty family members attended

○ Explained the SOC, importance of evaluation, and the need for family participation and guidance in all aspects of services and evaluation.

FIRST YEAR OF HOPE

○ Evaluation team presented reports of local SOC data

○ Taught family members about measurement tools, questionnaires, informed consents, SOC vocabulary and CQI

○ Divided participants in smaller groups for discussions to enhance sharing in the larger group

HELPING OUR PARENTS EVALUATE (HOPE)

○ CET named themselves “HOPE” for Helping Our Parents Evaluate.

○ Consistent attendance of 15 each meeting

○ Culturally diverse

○ Economically diverse
CATHARSIS OF THE GROUP DYNAMIC
- During the first two years, CET members gradually began to ask questions and offer some suggestions.
- Evaluators incorporated their suggestions into the evaluation process and reports.
- Evaluators provided reports to CET showing the changes made.

EMPOWERMENT IN HINDSIGHT
- The fact that evaluators asked their opinions, actually listened to their answers, and then immediately incorporated suggestions into reports and processes, while it was still fresh on their minds probably made the most progress in helping CET Members evolve toward empowerment.

MEMBERS GROW EMPOWERED
- Helped refine the locator form and devised policy and procedures for locating families for follow-up evaluations.
- When reviewing data, made connections and asked questions that lead to further analysis of the data:
  - Outcomes based on gender of Wraparound Facilitator and youth.
  - Questions regarding parents perceptions of grades and school improvement compared to the actual grades and behavior.
  - Questions regarding service hours and the relationship to improvements in youth's functioning.

POWER SHIFTS
- After the first two years, family members gradually took more control of CET:
  - Planned the agendas
  - Suggested analyses to evaluators
  - Suggested formats for the reporting and dissemination of data.

FAMILY EXPERIENCE STUDY
- CET felt the family voice/experience was missing from the National Evaluation.
- This frustration led to the Family Experience Study.

INTERVIEWER TRAINING MANUAL
- **Part I: Introduction**
  - Who’s Who in this Grant? Acronym Heaven
  - The Long and Winding Road to a Funded Evaluation Study
  - Letter to our Interviewers
  - Roles and Responsibilities of Good Data Collectors:
    - A: Professionalism
    - B: PROTECTOR of the SACRED DATA
    - C: Mandated Reporting of Child Abuse and Neglect
    - D: Scenario exercises

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INTERVIEWER TRAINING MANUAL

Part II: Pre-Contact: Case assignments and leaving messages

- A: Case Assignments
  - Eligibility
  - Contact Logs
- B: Leaving Messages
  - Returned Calls
  - Dealing with Rejection

INTERVIEWER TRAINING MANUAL

Part III: First Contact - Scheduling the Interview

- A: Scheduling the Interview
  - Phone contact must do’s
  - Sample phone transcript

INTERVIEWER TRAINING MANUAL

Part IV: The Interview

- A: Before you Leave for the Interview
  - What do you wear to an interview?
  - HOW DO YOU GET FROM THE CAR TO THE DOOR? “Beware of Dog”
  - WHAT IF’s?
- B: The Real Deal
  - 1: INFORMED CONSENT
  - 2: The Interview: Ready, Set, Action!
    - Review of Interview Procedure

INTERVIEWER TRAINING MANUAL

Part V– Final Paperwork

- Procedures for Interview
- Safety Plan
- Cultural Competence in Serving Children and Adolescents With Mental Health Problems
- Contact Log Example
- Rapport Building Exercises
- Materials Inventory - Don’t leave home without it!
- Addressing Problems and Concerns

INTERVIEW QUESTIONNAIRE

- Developed by the CET in consultation with professional evaluators
- Questions organized into four main topics with a primary question and several prompting questions under each topic
  - 1) Referral Experience,
  - 2) Engagement in Wraparound Process,
  - 3) Ongoing Wraparound Process
  - 4) Transitioning out of Wraparound.

FAMILY EXPERIENCE STUDY (FES) VOLUNTEERS

FROM OUR COMMUNITY EVALUATION TEAM (CET), HELPING OUR PARENTS EVALUATE (HOPE)*

Julia Owens
Yesenia Vasquez
Kelly Mays
Tonya Manning
Vivian Mayo Martin
Pamela Loper
Lisa Smith

*There were actually more volunteers than we could use for the FES from our Community Evaluation Team, in which each Member helped in some way with the study.

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METHOD

- Eligibility - participated in wraparound for at least 180 days and must have completed services (successfully or unsuccessfully)
  - N = 176 out of 210 closed cases at the time of study's implementation (in year 4 of services)
- 40 families randomly selected using a random number generator for participation (n=40)

METHOD

- Interviewers were randomly assigned an initial set of five families
- Spanish-speaking families were assigned to a bilingual interviewer
- Letter sent to the selected families
- Interviewers contacted families by phone to arrange at each family's convenience

METHOD

- Interviews conducted at family's home or other place of the family's choice
- If a family chose not to participate or could not be reached, a new family was assigned to the interviewer
- Evaluation staff was on call to interviewers to help if any questions or needs arose

INTERVIEWS

- Interviewers obtained written consent
- Interviews:
  - approximately one hour
  - recorded on audiotape
  - conducted in a conversational style
  - followed the general outline of the questionnaire
  - allowed freedom to ask follow-up questions
- Interviewers - compensated $25 per interview
- Interviewees - compensated $20 gift card

POST INTERVIEW PROCEDURE

- Audiotapes - transcribed by a team (5) consisting of family volunteers, professional evaluators, bilingual interns, and professional transcriptionists
- Spanish transcripts - translated into English for analysis
- Used an iterative process to reach consensus on identifying and coding themes

POST INTERVIEW PROCEDURE

- Narratives were analyzed as a whole, rather than one question at a time, as qualitative data should be analyzed
- Illustrative quotes were extracted from the narratives to support specific themes
- Quotes were coded into categories and entered into a searchable database to facilitate analysis
- Identifying information such as the names of individuals was removed from the quotes
FAMILY CIRCUMSTANCES PRIOR TO REFERRAL

- Recurring problems in school - mentioned in 75% of narratives
- Financial problems - 53%
- Problems with anger/violence - 53%
- Conflict within family - 50%
- Socially isolated / no support system - 43%
- Others denied or dismissed child's problems - 33%
- Employment problems - 23%
- Transportation problems - 23%
- CPS involved - 20%

They're saying, your kid's just bad ... so nobody's interested ... Nobody wants to get involved ... It makes me feel bad because it seems like I'm the only one that has a child going through this ... I was standing alone.

I promise you that every parent of a special needs child needs some kind of emotional support, because once you realize your child is not like other kids it's really hard not to go into a spiral of depression ... No matter what you do, you feel like you're failing ... You go into the bathroom and cry while your child naps, and you can't find the energy to get up and do your laundry.

INTRODUCTION TO WRAPAROUND INTERVENTION

- Mentioned initial anxiety meeting wraparound facilitator for the first time - 25%
  - If yes, anxiety overcome quickly - 90%
- Facilitator connected with child - 88%
- Facilitator connected with caregiver - 85%
- Mentioned importance of home visit - 55%

I was a little bit nervous because, you know, there was somebody coming into your home, getting in all your problems and everything.
I thought he [the facilitator] didn’t know how to speak Spanish like I don’t know how to speak English; I was surprised when he started talking to me in Spanish. He was bilingual.

The facilitator talked to my son on my son’s level and tried to understand his feelings and how he got the way he did.

I really appreciated the way that they [facilitator, youth coordinator, evaluator] sat down and talked to my child. Most people don’t want to talk to children. They just talk to the parents, but it’s really important for them to get to know the child themselves. And the child needs to know what’s going on. And I really, I really liked that part of it.

As I got to know her [facilitator], she became a big part of my family. I really was comfortable with her. I could talk to her about anything and my kids could, too.

[My son] used to stand up in the door and when he’d see [the facilitator] coming he would say, “Here he comes!” He looked forward to it.

ONGOING WRAPAROUND SERVICES

- Mentioned importance of not feeling alone, or knowing that others were going through the same thing - 53%
- Mentioned facilitator visiting child in school - 38%
- Mentioned outside influence of facilitator being important - 43%
- Mentioned that facilitator was inexperienced - 15%
[The facilitator went] to school, sat with my child and observed to see how things were going. And I think that really helped a lot ... Then, she came back and reported to me how things were going.

**WHOLE-FAMILY SUPPORT**
- Mentioned importance of addressing needs of caregiver - 50%
  - Caregiver needs addressed in their case - 59%
- Mentioned importance of addressing needs of non-target children - 59%
  - Needs of non-target children addressed in their case - 26%

I have a disability, too. I have adult attention deficit disorder, and I wish that ... I'd been offered some more support in managing my own problems so that I could be a better support for my child.

**SKILLS**
- Mentioned skills learned in wraparound - 65%
- Mentioned that they continued to use these skills after graduation - 58%
- Mentioned improved family relations or communication - 53%
- Mentioned child doing better in school - 48%
- Level of family empowerment
  - No apparent change - 30%
  - Described being more empowered - 43%
  - Described being a lot more empowered - 28%
- Mentioned being a better advocate for child as a result of the program - 25%
- Mentioned referring or helping other families - 13%

My child does not have a stable home environment because his mother is homeless and [he] just was jumping around from one relative to the other ... I only wish that there was a way ... [wraparound] could have helped [his] mom get stable and find a place.

[I wish] that it [wraparound] was for the whole family and not just the individual child ... In our circumstances, it would’ve been better to help the younger child as well, not just the older one.
“[Wraparound] taught her [daughter] that whole process of setting goals and brainstorming ... and being able to look at what she's doing and her behaviors, what's working for her and what's not working for her, and being able to make different choices based on that ... That's something that she's able to do [now].”

“I think going through this program really helped us to exercise our rights and to be very persistent.”

“Even if they're not finding the help for me anymore, they helped me find out how to find the help.”

“I think having a whole team of adults that are all following [the child’s] progress and goals and interventions and how well they worked, I think that really made a huge difference.”

“WRAPAROUND TEAM
- Had team meetings - 85%
  - Informal supports on team - 59%
  - Had the people that the family wanted on the team - 50%
  - School staff on team - 26%
- Caregiver had concerns about airing “dirty laundry” - 24%
  - If yes, concerns were overcome - 89%
- Caregiver has support system now - 48%”

“We got the team together. We talked about who should be on that team ... even one of his teachers would show up every meeting...and outside people, too. We are a very functioning church...and my mother and people that [played a role] in his life all the time.”
Really all of my support team came from inside Community Solutions. It came from my wraparound facilitator and people that were really on her team, so to speak, so now that I’m no longer in the Community Solutions program I am very much left without a team.

I wish that it [wraparound] didn’t end like it did. I wish it had ended when the person’s need was up, not when the time was up, because I still needed it and it left me so desperate. Things were still really bad when it left me ... I was still in crisis.

She [the facilitator] said, “We’re all finished,” and I’m thinking, I can understand us being all finished, but somewhere we took a bath and didn’t get dried off, you know? Because there’s a lot to be done when you get ready to graduate.

Felt they needed longer service term for their family - 48%
Were ready to leave services - 35%
Surprised by abrupt closure - 30%
Expressed understanding time and resources are limited - 28%

Honestly, I don’t think we were ready [to end services]... I still, almost a year later, think I still need help with this. But with a time limit and having so many people that need services, they can’t just keep you as long as you want to be in it ... Maybe they could think about extending it, maybe 18 months instead of just 12. Maybe with 18 months, I would have been better prepared.

Experienced turnover in their assigned facilitator - 38%
Change impacted services negatively - 60%
Dropped or “rushed out” as a result of changeover - 33%
Problems transitioning from one facilitator to another - 20%
Sense of emotional loss when facilitator left - 20%
We weren’t ready to discontinue services. It was difficult when [our facilitator] said she was leaving her job … It happened pretty quickly … There wasn’t much time to transition into anything else. We just got dropped.

I didn’t hear anymore from the team since the facilitator left his job.

Effects of Staff Turnover on Strengths-Based Child Outcomes

Overall Program Impression
(based on evaluator’s rating of tone and content of entire interview)

Overall Program Impression by Racial/Ethnic Group

There is tranquility at last at my home. I used to call the cops every day because of my daughter. It’s been three years since we ended the program and everything is great.
I’m in a better position now. I have a job now. My son goes to therapy. I have a home ... My son can open up a lot more now than he did when we were first started in the wraparound process. We’ve grown up. We’ve matured a lot.

**IMPLICATIONS FOR PRACTICE**

- Provide training and educational materials to school staff and others involved in children’s lives to make them aware of mental health warning signs and how to access available resources
- Increase community, agency, and facilitator focus on developing informal family supports

- Take measures to reduce staff turnover, such as increasing salaries and support for front-line staff, in order to improve outcomes for families
- Offset barriers to the hiring of bilingual Hispanic/Latino staff (e.g., relax educational qualifications, offer salary incentives)

- Hire wraparound facilitators who have had personal experience with childhood mental illness in their families
- Provide training and ensure facilitator competency in child development, mental health issues, and engagement skills

- Provide on-going supervision and support to facilitators
- Measure facilitator adherence to SOC principles
- Train wraparound facilitators to prepare families for the end of services by revisiting progress toward graduation at each meeting with the family

- Expand and promote family support groups
- Increase professional-family partnerships in designing, conducting and analyzing future research aimed at improving systems of care
To obtain a toolkit containing our report, our training manual, and other related items:

http://www.mentalhealthconnection.org/family_exp_study.zip

RECOMMENDATION COMMITTEE

- HOPE's other major project for the grant's final year was to form a Recommendations Committee which met to list certain issues discussed during CET meetings and mentioned in CS quarterly reports, which committee members felt effectively summarized information they would like to tell the grant administrators.
- The list was edited and expanded upon by the Evaluators to include recommendations gathered from respondents of the Family Experience Study. It is not surprising that most of the major recommendations from the committee were duplicated in the Family Experience Study's respondents. Problems leading to the recommendations list were easily recognized by those families in services. It was the intention of evaluators when forming the committee that the list would be considered carefully for future services and grant applications involving children, youth and families.