

FAMILY ENGAGEMENT IN EVALUATION: LESSONS LEARNED



FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

"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."¹

INTRODUCTION

The national Federation of Families for Children's Mental Health has advocated for inclusion of the family voice² in evaluation of the programs and systems serving their children since its inception in 1989. By 1998, the value of the family voice in evaluation was demonstrated to have such great potential that we began to develop and implement a variety of training curricula for families aimed at teaching usable knowledge, abilities, and skills related to program and systems evaluation. The development process was field-based and collaborative, meaning that families from diverse backgrounds and communities were influential to that process. They told us what information they needed and wanted to learn and how they wanted to learn it. They helped pilot the courses and gave significant feedback improving the first draft curriculum. Technical information came from our partners at the Research and Training Center at Portland State University, ORC Macro International, the Florida Mental Health Institute at the University of South Florida, and the Training and Technical Assistance Center at Georgetown University. Believing partnerships and relationships as key to stakeholder (family) engagement, we began to model positive family-evaluator partnerships by using families and evaluators as co-trainers.

The learning continues for everyone involved. As a community, we are becoming co-learners in a real sense. And, we are watching the trends of resident engagement or stakeholder involvement in other fields of study, such as the democratization of research and evaluation with Science Shops³ emerging to support the inquiries and efforts of average residents to improve the environments in which they live. Strategies that empower people to participate in the asking and answering of questions are being discussed in international conferences. It has been said that the questions we ask drive our future. Surely, we should all have a stake in those questions, how they are asked, and how they are answered, and, of course, how the answers are used.

Efforts toward family engagement in evaluation within the children's mental health field are demonstrating the value of this approach.

¹ FISCHER, FRANK. CITIZENS, EXPERTS, AND THE ENVIRONMENT: THE POLITICS OF LOCAL KNOWLEDGE. DURHAM & LONDON: DUKE UNIVERSITY PRESS. 2000. (P.39) ² "FAMILY VOICE" IS A PHRASE COMMONLY USED IN THE CHILDREN'S MENTAL HEALTH FIELD. IT IMPLIES THE PERSPECTIVE OF FAMILIES WITH CHILDREN RECEIVING SERVICES OR IN NEED OF SERVICES AND IS OFTEN USED IN DISCUSSIONS ABOUT HOW THAT PERSPECTIVE MIGHT INFLUENCE DECISION-MAKING. IN THIS PAPER, IT IS INDEED THAT PERSPECTIVE, KNOWLEDGE, AND LIFE EXPERIENCE OF FAMILIES WITH CHILDREN RECEIVING OR IN NEED OF SERVICES AS A PARTICULAR KIND OF EXPERTISE. ³ SCIENCE SHOPS ARE DEFINED BY THE IMPROVING SCIENCE SHOP NETWORKING (ISSNET) AS UNITS THAT PROVIDE INDEPENDENT, PARTICIPATORY RESEARCH SUPPORT IN RESPONSE TO CONCERNS EXPERIENCED BY CIVIL SOCIETY. WWW.SCIENCESHOP.ORG

CONTRIBUTIONS BY FAMILIES AS EVALUATORS

Families and evaluators working together create an opportunity for dialogue about meaning, value, need, strengths, solutions, human pain, and ways to heal. This is community building. This is about sustainable improvement in the services and supports that serve our children and families in the communities where we live.

Evaluations designed with information families have, are far more appropriate in their approach. Evaluation studies informed by the **family voice** are more culturally appropriate, for example.

- An evaluation team may know they should not approach a woman without asking permission of elders in a certain community.
- They may learn that such basic staples to individual assessment as eye contact have different implications in different cultures.
- And, the inclusion of families on the evaluation team alone may make families feel safer in responding to questions.

Data and study findings are put to use quickly by families engaged in evaluations they understand and support. Families, for example, have used data from the federally mandated evaluation of mental health systems of care for children and their families to inform their council members about funding decisions.

Families in a community with solid family engagement in evaluation are more likely to trust the process, more willing to provide data and respond to studies.

Families who understand that evaluation results will help determine the future of available services in their community are far more willing to stay involved in a longitudinal study.

We trust more value will be discovered and demonstrated as we continue this path of co-learning and partnering. But, while the value of family engagement in evaluation becomes increasingly evident, objections continue to be raised by some.

COMMON OBJECTIONS AND RESPONSES TO THEM

The objections to engaging families in program and systems evaluations do not come from those evaluators with families already on their teams. Those evaluators are telling us they won't go back to working without families. These teams are reaping the benefits of more useful studies and are having fun doing it. It is typically the evaluators and administrators to whom the idea is new, those being asked to try something they've never before done, who are objecting.

Perhaps such resistance comes from fears of losing one's professional identity and value; the threat of losing jobs if families take over; or being seen as incompetent if the partnership doesn't work. Such fears were explored in a dialogue begun in 1998 among a diverse group of partners and are documented in a monograph available through the Federation.⁴

⁴ THE NATIONAL PEER TECHNICAL ASSISTANCE NETWORK'S PARTNERSHIP FOR CHILDREN'S MENTAL HEALTH (1998). FAMILY-PROFESSIONAL RELATIONSHIPS: MOVING FORWARD TOGETHER.

OBJECTIVITY: A REASON TO EXCLUDE FAMILIES?

We often hear statements like, “Including the family voice will undermine the objectivity of our evaluation.”

Traditional academic research has long valued objectivity, or the absence of bias, as key to the quality of a study. Consider that any single person – or group of like-minded people – has their own worldview, their own values and beliefs, and (we all have) often-skewed ideas about other cultures or ethnic groups of people.

The more diverse the perspectives applied to any one issue, the more likely the final analysis will be balanced and free of bias.

Objectivity is, in fact, a prime reason for including the *family voice*.

CONFIDENTIALITY: A REASON TO EXCLUDE FAMILIES?

Another commonly heard statement from evaluators is, “We can’t include families because they’ll have access to information about other families. Confidentiality would be at risk.”

Systems and agencies are required to have policies and procedures in place to keep personal information and records confidential. They have to provide training for anyone with access to confidential information so that they understand and are able to follow all relevant rules ensuring confidentiality. Important considerations like language and cultural concepts of everyone involved in the study are important to making the training effective, the policies understandable, and the procedures practical to implement.

The experience of raising a child with mental health issues does not preclude a person’s ability to maintain confidentiality. Family members working on evaluation teams should be trained in the agency or evaluation team’s policies and procedures and held to the same level of accountability as any other team member.

Maintenance of confidentiality is trainable. It not a reason to exclude families from participating in evaluation.

WHAT? NO COLLEGE DEGREE? ANOTHER REASON TO EXCLUDE FAMILIES?

Some find it difficult to believe that people without formal or academic educations as evaluators or researchers can truly contribute value to a study.

Life experience develops a certain expertise – of culture, of community, of the day-to-day reality of living with a disability, or of the day-to-day experience of discrimination. This expertise is as valuable to informing decisions that impact one’s life as an academic education can be. While educated evaluators bring an expertise about methods and statistics, families bring an expertise that comes only from the experience of raising a child with mental health needs, struggling to get systems to meet their needs, losing their homes when financial resources run out, or loosing custody of their child to get public mental health services.

The expertise of families is extremely valuable to quality evaluation and cannot be replicated by academia.

COMMON CHALLENGES AND HOW THEY CAN BE OVERCOME

There are still challenges to overcome once an evaluation team commits to engaging families. Overcoming the common objections and knowing the true value of family involvement in the evaluation of programs and systems that serve their children do not, in and of themselves, guarantee smooth sailing.

MANY FAMILIES HAVE DEEP ANGER AND MISTRUST OF EVALUATION

We often get calls from evaluators or program administrators trying to engage families in evaluation who complain that families in their community must not care or not know anything about research and evaluation because they've asked, but families don't respond. They've presented to families, but they see the family members' eyes glaze over and they seem uninterested.

Truth is, families know a lot about research. Much of what they know comes from their collective historical trauma⁵. African American families remember the 1932 Tuskegee Syphilis Experiments in which 400 African American men, believing they were being treated for Bad Blood, were given placebo treatment while researchers observed the effects of their syphilis through its end stages. In the late 1970's a study with an impeccable research design examined the possibility that electric shock therapy could "cure" homosexuality. As recently as 3 years ago, a major U.S. university lost federal funding because its research on babies and young children from poor families intentionally exposed them to toxic levels of lead. They are but 3 examples of many studies that never should have happened! And, these are the stories about research that families pass on to their brothers and to their children, so they will not fall prey to similar kinds of violence.

Some evaluators don't know about or understand the impact of these experiences on entire populations of people. Some have no idea that their interviews are not resulting in completely truthful information, as families protect themselves, controlling what information they share, and appearing to be cooperative and compliant lest their people are harmed in another way. Many evaluators with the best intentions for children and their families have no idea how menacing and dangerous they are perceived to be.

What we've learned:

1. Families are more likely to trust an evaluator who knows about and is willing to acknowledge the abuse and violence in research history.
2. Families are more likely to trust and work with someone who will dialogue about those kinds of atrocities, how they happened, what harm they've done, and how they can be prevented in the future.
3. Families that learn the value of evaluation – how powerful it can be in informing decisions to improve child serving programs and systems – are more likely to commit to lending their expertise to evaluation.
4. Successful training for families includes the opportunity to learn ways to protect their communities and their people from the consequences of institutionalized racism and classism.

⁵ "HISTORICAL TRAUMA" REFERS TO THE COLLECTIVE DAMAGE OF TRAUMA PASSED FROM ONE GENERATION OF A PEOPLE TO ANOTHER. FOR EXAMPLE, SUICIDE, DEPRESSION, AND ALCOHOLISM RESULT, AT LEAST IN PART, FROM YEARS OF OPPRESSION, REMOVAL OF CHILDREN, LOSS OF LANGUAGE & CULTURAL WAYS, AND INVOLUNTARY RELOCATIONS, TO NAME BUT A FEW OF THE TRAUMAS VISITED UPON NATIVE PEOPLE.

CULTURAL AND LINGUISTIC CLASH BETWEEN FAMILIES AND THE WORLD OF EVALUATION

Evaluation and research, like any other area of expertise, has its own language that is neither easily understood nor does it have any apparent relevance to the everyday lives we are living with children with serious mental health issues. Families engaging in evaluation are, by definition, in the world of the evaluator. Evaluators, therefore, should take the responsibility to welcome, orient, and engage families. This includes moving to a kitchen table type of language and away from the exclusionary language of the expert.

In addition, the language differences between groups of people need to be overcome to ensure common agreement on meanings and concepts. I heard a story about a researcher who tried to be “hip” and talk the language of teenage girls in assuring them confidentiality. She told them, “What is said here, stays here.” The girls understood that to mean their stories would never leave the room. The researcher understood that to mean their identities would never be attached to their stories. The “story” has apparently been made into a movie and the meaning of the phrase “what is said here, stays here” is now said to be waiting for a judge’s ruling. This is truly an important gap to close between evaluators and families.

Something we discovered by accident in our training was that families and evaluators not only use different languages and come from different orientations, but they often don’t understand one another’s needs or limitations. We were in the middle of a role-play between an advocate and a researcher when it became apparent that the advocate – intending to be a great partner by using the data – shared her plans to run to her legislature with “these findings.” The researcher literally collapsed into a chair, exclaiming she would lose her job if the findings were released before going through the appropriate channels of clearance in the university supporting the study.

We began to develop a list of differing needs and obligations owned by different people during the process of evaluation. For example, when designing the study an evaluator may be concerned with funding restrictions, internal review board clearances, validity and reliability. She is already planning to defend her study to her peers as sound. Meanwhile, a family member would be concerned with getting data that helps her community quickly; with implementing the study at a time that doesn’t interfere with traditional ceremonies or religious observances in her community. We’ve found that an evaluation team with diverse members can build a cohesive team and create better collaborative plans if they first take time for each member to explain his or her unique set of needs and concerns for each stage of the evaluation process. Team members cannot cover one another’s backs if they have no idea what their team members are facing.

RACISM, CLASSISM, AND POWER ISSUES

Who owns the data? Who sets the research agenda? Who defines the problems? Who defines the outcomes? Who is to say what “success” is or what “better” is? These are questions that lead us to conclude that one of the biggest challenges to successful partnership between families and evaluators – to real family engagement in evaluation – are issues of power. Who defined homosexuality as a disease? Who set the research agenda when African American men were given placebos to treat Bad Blood? Those with the power did.

In children’s mental health, who determines what systems outcomes should be achieved and, therefore, assessed? For example, who determines the measures of quality of a health care clinic? Is it the money saved from one fiscal quarter to another? Is the phone answered on the second ring? Is it the hours the clinic is open in the neighborhood where the people live? Is it the percentage of minority youth who are referred to out-of-state residential care? Is it the elder who sits behind the receptionist’s desk and greets clients in their own language? These are questions of power. They are also questions about racism and classism. What are the underlying dynamics that limit authentic and equal partnerships in the studies of the systems serving our children and their families?

Our most pressing lesson to date is that we must delve further into the murky waters of discrimination, racism, classism and how these issues support existing power structures. These issues must be part of the exploration for solutions that advance the field and improve systems and communities. Perhaps communities creating their own Institutional Review Boards to control research done on their community and people; or deep dialogues; or the personal work of unlearning the “-isms” we have all grown up with, are some of the improvements.

CONCLUSION

The people making family-evaluator partnerships work are doing very important work. They are helping to move children’s mental health research and evaluation closer to the most critical questions.

Objectivity, confidentiality, and non-academic expertise are not reasons to exclude family engagement in evaluation. They are, instead, the very reasons family members should be included. Anger and suspicions of families may be seen as challenges to a program’s ability to engage families, but properly addressed actually provide a critical opportunity for deep and healing dialogue for entire communities of people. Addressing the cultural and linguistic differences between the lives of people and the academic world of evaluation can serve only to clarify issues and terms and add precision to evaluative studies. And, finally, addressing racism, classism, and power issues – can we even imagine the healing possible if those dialogues were to begin? If it is true that the questions we ask drive the future, it should also be true that no one perspective should be excluded from formulating questions and finding ways to answer them.



Authored by Elaine Slaton.

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