



FAMILIES AND COMMUNITIES IN EVALUATION

Most of us in Indian Country have had plenty to do with evaluation during our lifetimes. We have answered surveys, sat in on focus groups, filled out forms, and sometimes suffered from the erroneous results. We have been subject to study since the earliest periods in the history of research and evaluation. Many times those studies did nothing to benefit us; more times than not, they resulted in harm.

More and more programs want to involve consumers in the evaluation of their program and services. Not simply in the role of subjects on satisfaction surveys and focus group reports but at the very core of evaluation. From designing the questions to the dissemination of the results, family members are beginning to take their place at the table.

Until recently, families had little role in evaluation. If they were involved in an evaluation or research project, they were relegated to data collection. Without community and family member involvement in defining the questions, assisting in the selection of instruments and outcome measures, and consulting in the interpretation of the results, researchers are often left with an incomplete and sometimes inaccurate picture of what they are studying. This can lead to the production of information that is not helpful to communities and sometimes even has detrimental results. For example, a research project conducted in an inner city neighborhood concluded that this particular neighborhood had the highest murder rate in the city. This left the impression that the neighborhood was dangerous and the residents were criminals. This did not reflect the experience of the members of that community. Upon their further investigation, it was found that not a single murder was committed by anyone in the neighborhood, nor were any of the victims from that neighborhood. In fact, murders were often committed elsewhere and the victims were transported to the neighborhood. As you can imagine, the



second conclusion—arrived at with input from the community—differs greatly from the first.

When it comes to planning and delivering services to communities, research and evaluation are key. Research data are often used in the development of services. Evaluation data become essential in determining the necessity of a service and/or its need to change. In response to the information gathered, decisions are made that affect policies, programs, support, and the expansion or termination of services. It is imperative to have the most accurate and appropriate information available in order to make those decisions.

One of the best ways to ensure the accuracy and appropriateness of the information gathered during research projects is to include the voices of family and community members meaningfully in the evaluation process. What is more, when researchers and evaluators work collaboratively with community members, the information that is produced can become an advocacy tool that validates the experiences of families and communities. This information can then be used to motivate policy and program decisions which reflect the community's sense of its own needs. On the other hand, research studies—especially when they are conducted without community input—may motivate decisions that have a negative impact.

Family perspectives are particularly crucial in determining what sorts of outcomes to include in research and evaluation. Families use a set of measures that are not often reflected in outcome studies. How many times did I get called from the school this week or how many meals were we able to share together without interruption? Did the meetings with all the various agencies in our lives, the intensive therapy sessions, and the various evaluation requirements allow us time to be a family and to practice the suggested behavioral modification? Are we closer to a path of healing or further away? Are our days filled with

crisis management and financial burden beyond our limits? Are our children headed toward a bright future with possibility and potential within the boundaries of their respective diagnosis or are they headed into the agency abyss to be lost to limited lives? Will they be alive? Will they survive the systems set in place to help?

These are the very real performance measures in our daily lives. First and foremost we seek safety for our children. We need to know that our children are not at the disposal of drug companies in collusion with research projects that experiment at the expense of our children's lives. We need to know that, when we find our sons or daughters in need of self protection, the environments they are placed in will, first, do no harm. We need policies to ensure that suicide prevention means that our children are in a safe space without access to items that they could use for self-harm, that one to one observation does not somehow become periodic checks at the discretion and convenience of staff. We need strict enforcement of standards around restraint and seclusion. We have measured the outcomes at the gravesites of our children. The first outcome we seek is for our children to live.

The next outcome we seek is for our children to have some quality of life that ensures their ability to be happy and productive members of their community. How do we measure that? We measure that by some of the same indicators that the research world uses. We measure that by success in school and progress in educational plans. We measure that by decreased involvement with juvenile justice and outofhome placements. But we also measure that by the number of times we have had "emergency" visits to doctors and therapists in a month. We measure that by nights at the supper table together without conflict. We measure by our own set of indicators: sharing a ceremony or celebration, being "in this together," making it through a school suspension or adjusting to a new medication. As family members we need our strengths acknowledged, our resources valued, and our children treated with love and respect.

We can tell you when systems are not working. We can tell you that giving up custody to the state in order to access financial support for services is not helpful. We can tell you that systems set up to punish and not instruct are not helpful. We can tell you that when our natural resources, our cultural norms, our definitions of family are not supported, it is not helpful.

In research and evaluation, many of us feel there should be "nothing about us, without us." We need to be at the table when the outcome measures and evaluation

strategies are being developed. We need to "partner in order to prove" what our experience has taught us. We need our informal community supports to be included in the therapeutic measurements. We need the development of tools that fit with our cultures and communities. We need our strength and knowledge coupled with the skills and tools of the research and evaluation world to foster meaningful improvements in outcomes for our children.

Family members who want to be at the table can begin by learning about evaluation and research. What is being researched? Why is it being evaluated? Who is paying for the research? What will be done with the results? How do you know if the results are providing the

You say

There is no difference
between you and I.

Who gave you permission
to deny our
separateness?

You plead ignorance
as an excuse
and wear it like protective clothing
while I am to be examined
naked
at your minority board meetings.

I am to understand you.
your language
your practices
your protocol

Your history books tell
your story
mine
is nowhere to be found.

I have searched
the volumes bound and stacked
in your great buildings
of higher learning.

Don't tell me you know who I am
by those publications and administrations

Our elders
my teachers used to say bi-inabin
"Come, look"
Remember, this is our way.

You say there are no differences
between you and I
to accept that would be to
see my culture die.

-Shannon CrossBear

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true picture or telling the whole story? Who owns the information and how will it be used?

Researchers need to know if the question asked is the right question. Will the question itself create harm? Are the instruments used culturally appropriate? Can the methods of gathering data be used in the community? Once data is gathered, how is it analyzed? Who interprets it? Will it contribute to positive outcomes for the community? The voice of the families is essential in both asking and answering these questions.

As we seek to have the conditions and circumstances within our communities addressed, we need to formulate our responses based on reliable information about outcomes that matter to all of us. In order to be at the table together, both researchers and family members need to expand their knowledge base to include the other. Recent efforts are helping us move toward this end. The Federation of Families for Children's Mental Health is offering trainings on the evaluation process to family members. The three course series on "The World of Evaluation (How to Understand It, How to Work in It, and How to Run It)" prepares family members to be effective members of research evaluation teams. The courses are cotrained by a family member and an evaluator to give full voice to the information and issues from both perspectives.

Collaboration like this can help us find ways to gather high quality information that truly promotes positive outcomes in our communities.

Ultimately, the outcomes we seek will be measured by future generations. In my community, we have a belief that the decisions and actions of today will impact seven generations to come. Our children and our children's children will decide whether we have done that in a good way.

For more information on "The World of Evaluation" training, contact the Federation of Families For Children's Mental Health, 1101 King Street, Suite 420, Alexandria, VA 22314, (703) 684-7710. The RTC is collaborating with the Federation of Families to evaluate "The World of Evaluation" trainings. For information about this research and to view recent presentations and products, visit www.rtc.pdx.edu/pgProj/Evaluators.php

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