

## Q&A: A New Approach to Assessing Family Engagement in Health Care Systems

Below are responses to questions the panel was unable to answer during the webinar.

### Respondents

- **Beth Dworetzky**, Project Manager, Family Voices
- **Susan Chacon**, President, Association of Maternal and Child Health Programs and Title V Director for Children's Medical Services, Children and Youth with Special Health Care Needs program, New Mexico
- **Nanfi Lubogo**, Co-Executive Director, PATH Parent to Parent/Family Voices of Connecticut

### Q&A

#### Family Voices Assessing Family Engagement in Systems Framework and Tool:

**When will the family engagement assessment tool be publicly available?**

**Beth:** We expect to share the tool in Summer 2019. We are currently looking for pilot sites, if you are interested, please email [Beth Dworetzky](#).

**It seems that the domain of the assessment is relevant to the work with families in general not just families with children facing a health challenge. Can you use this tool within early childhood education center-based settings?**

**Beth:** Yes, the tool has been designed for use in a variety of settings where children, youth, and families are served. It is not exclusive to the health care sector or to families with children and youth with special health care needs.

**Our work has engaged families for many years. I notice a trend away from family advisory boards and toward family members being a part of the team. I am curious what tools are available to measure engagement in this model. I often find it hard to separate the family contribution from anyone else's since everyone is seen as an equal part of the team.**

**Beth:** The goal of the Family Engagement in Systems Assessment Tool is to assess a team model of family engagement. Even when family members are part of the team, they still have their own perspective to share about how supported they felt, if they were engaged in all phases of the initiative, etc. Scoring the tool from the organization staff and family points of view can be a way to learn how each team member views family engagement and identify areas of strength and any areas for improvement.

**Our health system serves a population of patients that come from a wide area, rural and poor. Over 65% of our patients are on Medicaid. Our senior leaders say that they cannot compensate or pay expenses to families and patients because of a Centers for Medicare & Medicaid Services (CMS) ruling that says they cannot be seen incentivizing patients. This is an age-old issue and I just wonder are we ever going to be able to get past it?**

**Beth:** Many organizations contract with a family-led or community-based organization to manage stipends for families who participate. You might consider arranging a similar type of contract with the [Family-to-Family Health Information Center](#) in your state, or with another family-led or community-based organization - perhaps one that provides services or supports to your patients. Family Voices and other family-led organizations are advocating for compensation that is appropriate to family needs and cost of living in any given area.

## **PATH / Family Voices CT and the NERGN Project:**

### **How did you address cultural/linguistic competency?**

**Nanfi:** Aside from the obvious methods of providing materials/training in different languages, we offer outreach and training in the manner that best suits a community that we are trying to reach. For instance, training/outreach can be “classroom style,” “conversational,” or “round table” in a group setting. We never lecture and instead learn about needs directly from the community itself. We listen. We engage with the community and involve them directly in the project. We also ensure that health information is provided to families in a manner that is understandable to families at all literacy levels.

### **How would you reach underserved people if they are not connected with a cultural broker?**

**Nanfi:** A cultural broker is just another term for a community leader or organization. Many underserved people connect to and receive services from their community church or community center. Most times we receive referrals from these entities or a community health center.

### **Is there a cultural competence training that you would suggest or recommend?**

**Nanfi:** I recommend resources from the National Center for Cultural Competence (NCCC) at Georgetown University. They offer a wealth of information on cultural diversity and linguistic competence. Materials and self-assessment tools are available for download: [nccc.georgetown.edu](http://nccc.georgetown.edu)

## **Children and Youth with Special Health Care Needs Program, New Mexico:**

### **How have you handled poverty issues in family engagement?**

**Susan:** That is where the community family-based organizations can really help as they are representative of families in the State. We fund the organizations and then they filter those funds back as stipends. We also survey our clients that we work with directly and since we are a social work-based program we help families to address poverty issues as part of wholistic care.

### **What data sources do you use to identify the needs and priorities for the CYSHCN block grant portion?**

**Susan:** We use the national data set from the National Survey of Children’s Health, NM Medicaid data, IDEA parts B and C, and our Title V database for CYSHCN.

### **How can one contact Education of Parents of Indian Children with Special Needs (EPICS)? Is this nationwide?**

**Susan:** They are a New Mexico program, [epicsnm.org](http://epicsnm.org), 888-499-2070