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Interview Methodology and Questions

The following describes the qualitative interview methodology and interview and focus group questions used in development of the brief on individual and family engagement of the Medicaid population.

Methodology:

A broad range of stakeholders were engaged in exploring the successes and challenges of patient and family engagement with the Medicaid population, including Medicaid patients and families, state agency representatives, clinicians, researchers, innovative program leaders, representatives of managed care health plans, and experts in the fields of motivational interviewing, trauma informed care, health literacy, and patient activation. These in-depth interviews inquired about both an individual provider's experience in engaging with patients and families, and—for those receiving Medicaid services—experiences that promoted or discouraged their ongoing engagement with direct health care services and/or the agency itself. Each recipient was asked to share insights and ideas they had for Medicaid Directors, staff, health care providers, and others to improve or support their higher level of engagement.

The researcher used a collaborative process to identify interviewees and refer them for consideration. Instrumental was the use of the Institute of Patient- and Family-Centered Care's (IPFCC) broad network of health care professionals and patient and family advisors. Also, the interviewer solicited recommendations from organizations working closely with Medicaid state programs, and from interviewees. More than 70 individuals were invited to be part of the study. Interviews were scheduled for those who accepted the invitation. Forty-one (41) participated in individual interviews, 8 participated in a focus group interview, representing the following perspectives:*

- 10 Individuals receiving Medicaid;
- 4 Parents of children on Medicaid;
- 6 Medicaid staff or directors;
- 9 Practicing clinicians;
- 10 Programs providing direct care services;
- 6 Managed Care Organization staff;
- 5 Researchers; and
- 5 Others.

*Some individuals were in more than one category.

Each interviewee or focus group member received the following information prior to the interview and received the list of interview questions beforehand:

> "For the purpose of this interview, we are defining patient and family engagement as an active partnership between patients, their families or representatives and health care clinicians, staff, and leaders. Collaborative patient and family engagement is a strategy for achieving a patient- and family-centered system of care. Patient and family engagement occurs at four levels:

- At the clinical encounter, patient and family engagement in direct care, care planning, and decision-making.
- At the practice or organizational level, PFE in quality improvement and health care redesign.
- At the community level, bringing together community resources with health care organizations, patients and families.
- At policy levels locally, regionally, and nationally.

We will explore five areas with you on this topic of Patient and Family Engagement. We anticipate this will take NO more than 60 minutes and probably less. Your responses will be anonymous and aggregated with other themes and ideas shared by others. If I find that the information you provide is so compelling that sharing specifics would be of value to the brief, I will contact you to seek your permission for that level of disclosure."

Questions Posed in Individual Interviews:

Experience:

1. Describe a time when you have participated in or observed strong and effective patient and family engagement. Why do you think it was successful?
2. Have you discovered approaches to patient and family engagement that were not effective? What are your theories/stories about the failure of those efforts?

Insight

1. As you have sought to engage patients and families in policy or program development, evaluation, or care, what has worked surprisingly well?
2. What has been challenging?
3. What learning would you wish to share with others?

Measurement:

1. Have you tracked or documented the outcomes of effective interventions to increase patient and family engagement?
2. If not, what do you believe would be important to measure?
3. Are there things you are already measuring that should be monitored as changes are made to improve patient and family engagement?

Advice/Action/Interventions:

From your perspective, what would you find most useful for Medicaid Directors to do to achieve the following behaviors in the following areas:

1. To help engage patients and their families in their own care.
2. To encourage providers to effectively partner with this population.
3. To invite Medicaid patients and families to participate meaningfully in the transformation of health care programs and services.

Network and Conclusion:

1. Is there someone you might suggest I contact who has experience inpatient and family engagement and could add value to this issue brief?
2. Are there any other comments you would like to share that may not have come up in our conversation today?

Focus Group Questions Posed with the Community Health Engagement Advocates of CareOregon:

1. Think of a time when you been an active partner in your care, or participating in activities where a group is discussing improving care, changing policies or evaluating a health care service. What did you do? What did others do to help you be a full partner? Was it successful? Why?
2. What are barriers to your active participation in these activities?
3. What have others done that encourage your engagement?
4. What has been challenging for you to maintain an active role in your care?
5. What has been challenging to participate in the other levels of participation in improving programs and services?
6. What would you like people working in Medicaid agencies, health plans, doctor's offices to know that would help them be effective in encouraging or supporting your engagement?

From your perspective, what would you find most useful to achieve the following behaviors:

1. Help engage patients and their families in their own care?
2. Encourage providers to effectively partner with you and other Medicaid enrollees?
3. Active involvement of Medicaid patients and families in groups that are working to improve/transform health care programs and services?
4. Are there any other comments you would like to share that may not have come up in our conversation today?

The methodology used created an opportunity for these diverse experts to share their insights about the process of effectively engaging individuals and families receiving Medicaid services. Insights gleaned provide a rich context for key content included in the Medicaid brief on individual and family engagement.