

Importance of families and understanding how to assist families/caregivers to access services



Introduction

The information and dates in this presentation are accurate as of the date of this presentation or delivery of content



Overview

- Importance of Families
 - Family Driven Care Framework
- Common Challenges in Access and Utilization of Services
- Engagement Best Practices: Strategies to Address Barriers
- Resources

Importance of Family and Youth Involvement in Services

- It is essential at each phase of the treatment process, including assessment, treatment planning, implementation, monitoring, and outcome evaluation, that family and youth are involved.
- This includes:
 - Family and youth are given information needed to make treatment decisions.
 - Family priorities and resources must be identified and should drive care.
 - Families and youth collaborate actively in developing treatment plans and in identifying goals and outcomes.
 - Families and youth participate actively in monitoring treatment outcomes and modifying treatment

Providers, along with Managed Care staff, should be working to ensure that family/youth have all the information needed to make informed decisions.

What is Family-Driven Care (FDC)?

- Family-driven care means families are expert partners in the care of their children and should be given a decision-making role in their care.
- FDC accomplishes the following:
 - Acknowledges the family as a constant in a child's life.
 - Builds on family strengths.
 - Supports the child in learning about and participating in his/her care and decision-making.

FDC is a framework that can be used by treatment providers and Managed Care staff.

Guiding Principles of FDC

Families and youth...

- Are given accurate, understandable and complete information
- Are supported to gain the skills needed to advocate for their child and family and participate in treatment/services
- Work as partners to set goals and make choices in planning
- Provide direct input into decisions that impact services
- Share the responsibility for outcomes

FDC Values of Change

- **Family-Centered** - Focus on the family and each individual family member's strengths, talents, interests, values and beliefs.
- **Family Involvement** - Family members (parents, siblings, primary caretakers, etc.) are encouraged to be a part of treatment in some way. There's an emphasis on strengths and expertise of family members.
- **Family Choice** - Focus on the family identifying, evaluating, and choosing options.
- **Hope and Growth Potential** - Belief in each person's potential to learn and grow. Build confidence by supporting step-by-step progress.

What does FDC look like?

- FDC shifts the experience from provider or authority-driven to collaborative/family-driven.

Indicator	Provider-Driven	Family-Driven
Source of Expertise	Professionals and agencies	Child, family, and network
Relationship	Child and family viewed as dependent client expected to carry out instructions	Partner/collaborator in decision-making, service provision, and accountability
Orientation	Isolating and “fixing” a problem seen as residing in the child or family	Ecological approach enabling the child and family to do better in the community
Assessment	Deficit-oriented	Strengths-based
Expectations	Low to modest	High
Planning	Based on agency resources	Individualized for each child and family
Access to Services	Limited by agency’s menus, funding, and staffing schedules	Comprehensive and provided when and where the child and family require
Outcomes	Based on agency function and symptom relief	Based on quality of life and desires of child and family

Common Challenges in Access and Utilization of Services



Research shows....

- Only approximately half of children who meet criteria for mental health disorders receive any form of treatment
- African American and Latino children have been shown to be less likely to have their mental health needs met
- Children in low-income families have been found to have the lowest rate of utilization of services, and once in treatment, they were more likely to end treatment early or drop out
- Challenges exist at various points, including the family level, provider level, agency level, and systemic level. For example,
 - Parents may not know what are appropriate services and how to access them
 - Providers may not be using best practices for engaging diverse families
 - Agencies may set policies or protocols that limit access and utilization
 - Systemically, there may be a shortage of providers or services in a certain area

(Merikangas, He, Brody, Fisher, Bourden, & Koretz, 2010; SAMHSA, 2010; Bringewatt & Gershoff, 2010; RAND, 2001)

Barriers to Service Engagement



Concrete Obstacles :

- Cost of care
- Services not available in own language
- Not knowing where to get help
- Difficulty in scheduling appointments
- Location of facilities
- Transportation
- Difficult to get time off from work
- Competing needs (e.g., other appts)
- Complex system to navigate

Perception Obstacles:

- Fear of being prescribed medication that would have negative side effects
- Stigma; being viewed as weak
- Feel as if they will be blamed for problems; judgment
- Perception of quality of services
- Attitudes towards mental health services

(RAND 2011; Hoge 2004)

Identifying Barriers

- Which of these barriers have you seen in your work?

- How have you addressed barriers you have seen?

Barriers to Engagement (cont.)

- Concrete

- Time constraints, childcare, transportation, competing priorities, getting kid there

- Perceptual

- Treatment expectations, preferences, acceptability and treatment match, treatment demands, perceived need for services, attitudes about mental health, negative prior experiences, perceived stigma, therapeutic alliance

- Mental Health Issues and Family Ecology

- Caregiver depression, sibling health/mental health issues, multiply stressed, isolation, trauma, substance abuse, family and marital conflict

Barriers to Engagement (cont.)

•Cultural

- Diverse caregiver values, help seeking traditions, beliefs, language, life experience, cultural relevance of program, agency, perception of provider
 - For immigrants - trust of authority or have own authority structures
 - For minority group families - racial discrimination, community social stigma, shame, doubts about provider cultural competence
 - Implicit bias, lack of providers who are reflective of communities served

•Systemic

- Source of referral - mandated or perceived coercive, child "taken away" fears, confidentiality concerns
- Poor service coordination - fit, gaps, wait-lists, program site/hours, agency/worker resources & responses
- Poverty, violence, substance abuse, community skepticism

Research Findings on Barriers to Service Engagement



- Not all barriers are “equal.”
- Perceptual barriers (e.g., stigma) and prior negative experiences have been shown to have the greatest influence on initial and ongoing engagement.
- Addressing perceptual barriers may be more important than focusing only on concrete obstacles.

Engagement Best Practices: Strategies to Address Barriers



Engagement is about motivating and empowering participants to recognize their own needs, strengths, and resources and to take an active role in changing their life.

Basic Goals of Engagement

Here are some key basic steps to consider when working with a family:

1. Clarify the need for services
2. Increase youth and caregiver investment and efficacy in services
3. Identify attitudes about previous experiences with care and institutions; attend to perceptual barriers
4. **PROBLEM SOLVE! PROBLEM SOLVE! PROBLEM SOLVE!**

Strategies to Engage and Empower Families



- Providing positive feedback
- Instilling hope
- Reinforcing strengths
- Fostering resilience
- Helping to identify barriers to implementing change within their day-to-day life and help problem-solve around those barriers
- Taking time to understand the family's perspective
- Building trust and a collaborative helping relationship with the family
- Understanding the impact of cultural and racial differences between provider and family

Acknowledge and Address Fears

- Families may have concerns about privacy and confidentiality. Those who do not trust the provider or feel the information shared will not be held in confidence are also at a greater risk for dropout
- Cultural and racial differences between the provider and family can lead to misunderstanding
- Reserve your own judgement – focus on acknowledgement and acceptance of differing views and perceptions of experiences

Messages to Communicate to Families

- “It sounds like you have been working very hard to resolve these difficult issues.”
- “What do you think your child could benefit from?” (as the parent is the expert on his or her child’s needs)
- “I know what the _____ (school; doctor) said, but what do you think you need?”
- “Thank you for helping us to understand more about your child and your family. This will help us to better help you.”

Engagement Best Practices

It's Everyone's Job!

- Greeting the families
- Making your families feel welcomed
- Engaging families/youth as a team / collectively
- Not a single approach - it's a multi-level approach

Engagement Best Practices

Problem-Solve Barriers



- Every contact with a family is an opportunity to explore potential barriers to obtaining services
- Identify and address specific obstacles, e.g., transportation, how to access services, etc.
- Identify and attend to any perceptual barriers, e.g., caregiver expresses not wanting a service because they had a past negative experience with a similar service

Engagement Best Practices

Focus on Practical Concerns

- Be ready to schedule follow up appointments or referrals sooner than later
- Families often need help negotiating with other “systems”
- Responding to concerns provides an opportunity for staff to demonstrate their commitment and capacity for help

Engagement Best Practices

Validation

- Validation refers to communicating acceptance of a client/family/youth and his/her thoughts, feelings, statements, and behaviors.
- It involves stating that behaviors may have been justifiable (not necessarily adaptive) given the person's history or current situation. It does not mean that you agree with the behavior or feeling or that it was appropriate.
- Validating, strength-based comments are also appropriate for the staff/provider-client relationship ("Yes, I can see that you have made an effort to follow through with treatment.") and can be used to positively reframe less successful efforts ("I understand that you hate taking your medication, but I can see that you care about your health because you come to your appointments.")
- When people feel understood, they are more open to receiving help.

Engagement Best Practices

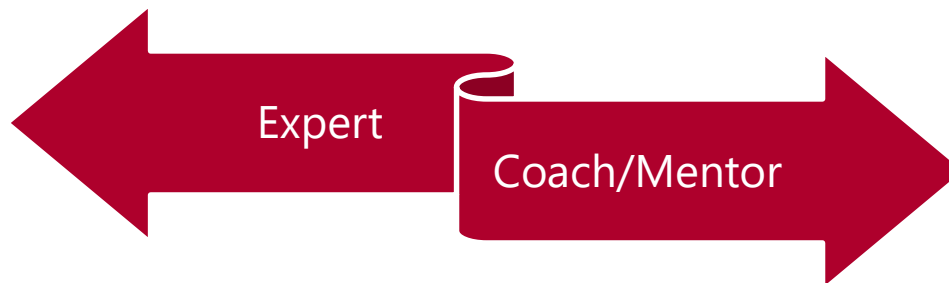
Culture of Feedback

- Create a space for family/youth to feel comfortable to express their concerns and ask questions
- Ask family/youth to explain what they have heard you say and anything they did not understand

Engagement Best Practices

Relationships and Collaboration

- Build a trusting relationship
- The provider/clinician needs to establish trust by acknowledging the power dynamics that have existed in traditional service delivery models with staff having control.
- The provider/clinician must be transformed from the dominant provider to a coach or mentor helping individuals to develop skills and grow.



Collaborative Working Relationship

- Balancing need to obtain information with helping the client “tell their own story”
- Explicate roles and responsibilities of all going forward towards shared goals
- The “We” is created – the collaboration is felt by the client through the use of “we”

Hatch, Moss, Saran, & Presley-Contrell, 1993

Collaboration can start with the words we use...

A. Some examples of “Watch Words” that can demean people:	B. An example of another way to describe someone in distress.
<ul style="list-style-type: none">◆ “attention-seeking”◆ “manipulative”◆ “chronic”◆ "treatment resistant,"◆ “acting out”	<ul style="list-style-type: none">◆ Donna appears to have a hard time getting what she needs. She often goes to extremes to get someone to talk with her because she has been so neglected in the past.

- Language and labels are powerful and can set a judgmental and negative tone which reduces collaboration.
- When reviewing documentation, Column A words may indicate a lack of use of strengths-based engagement. Discuss alternative ways of viewing the same behaviors. How can we shift the language?

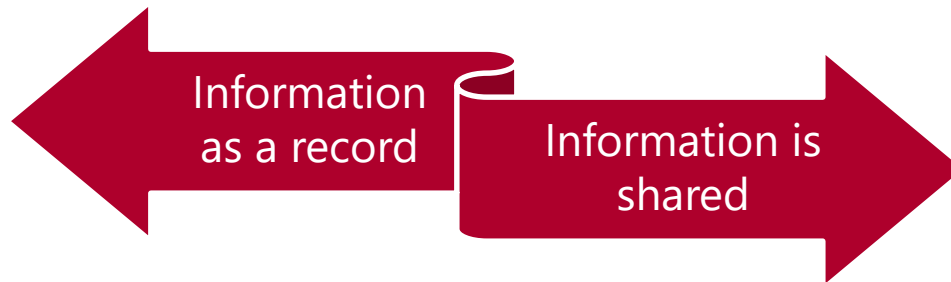
Prescott, Soares, Konnath, & Bassuk (2008). *A Long Journey Home: A Guide for Creating Trauma-Informed Services for Mothers and Children Experiencing Homelessness*. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration

Engagement Best Practices

Information is Power

Inform families of the benefit of partnering with you to meet their goals

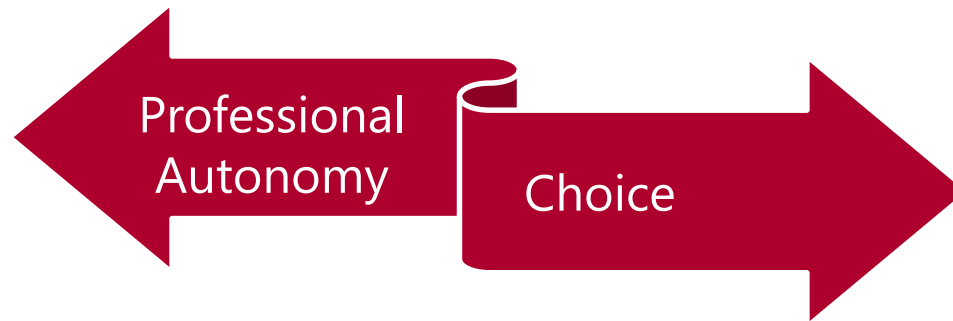
- Discuss expected duration and how services will be provided
- Inform families that services will be customized according to their needs and change as necessary
- Explain your role as coach to help guide them through their learning.



Engagement Best Practices

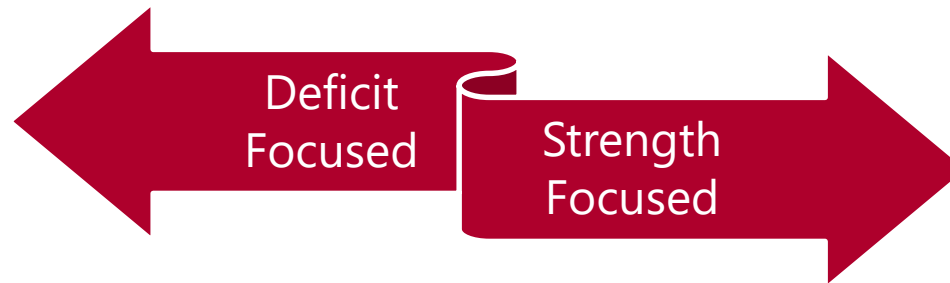
Services Negotiation

- Negotiate a common understanding of the nature of the family's problem and the manner in which it could be addressed in therapy/services
- Respect the family's choice and self-determination



Engagement Best Practices Family/Youth Empowerment

- Incorporate their services preferences.
- Instill general hope about the process.
- Focus on what they are doing well.



Engagement Best Practices

Identifying Strengths

- Promotes alignment.
- Reminding clients/families of all they have overcome and how resilient they are.
- Ask: "What's working well for you?"
- Help elicit something positive that the client/family/youth can say about themselves.

Engagement Best Practices

Reframing



Additional Content: Discussion Cues and Resources



Resources

<https://www.ctacny.org/services-best-practices>

Engagement of Family and Children Category has a number of webinars on Family Driven Care and other engagement topics.

What Do We Know About the Benefits of Caregiver Involvement?

- Parenting matters: positive caregiver-child interaction is a vital protective factor across all ages
- Caregiver involvement has consistently been associated with improved child outcomes.
- Youth who receive caregiver-child interventions may improve more than those who receive individual child treatments.
- Family-level interventions, such as behavioral caregiver training, family skills training and family therapy can significantly improve child outcomes.
- Almost half of evidence-based treatments for youth include caregivers in sessions.

Haine-Schlagel, et al. 2012; Nock and Ferriter 2005; Dowell and Ogles 2010; Karver et al. 2006; Dowell and Ogles 2010; Huang et al. 2005; Sexton & Alexander, 2002; Kumpfer & Alvarado, 2003; Weisz, Jensen-Doss, & Hawley, 2006

What would make a family's experience perfect?

Consider one of your first contacts with a client/family/youth. Describe what would make the experience perfect for them.



The Successful Process of Involving Caregivers

- Begins with the caregiver feeling respected and heard
- Reflective listening and validate the parent's experience
- Acknowledge the struggle and recognize strengths
- Use reframing liberally to decrease blame, sense of failure, hopelessness
 - e.g., change self blame to regret
- Clarify goals and needs
 - Seek feedback on the match between caregiver expectations and services
 - Prioritize – helps keep focus and align treatment as issues arise in the work
 - Transparency in your evaluations
- Identify barriers and concerns, collaboratively problem solve
 - Discuss options/ideas – What does the parent think may help? What has worked before?
- Instill hope
 - Tap into hopes and dreams
- Use motivational interviewing strategies to respond to ambivalence, increase intention to participate
- Respect and incorporate caregiver perspective in the treatment plan
- Empower caregivers and foster self-efficacy
- Thank caregivers for attending as, without their participation, the child's progress may be limited