Objectives

Participants will learn:

• What it means to have families take on the primary role in decision making when it comes to their child’s care and well-being.

• How to avoid the “expert” model of interacting with families and instead adopt a more collaborative approach to decision-making, goal-setting, and record-keeping.

• How to assist families with making their own decisions as they navigate their own care.
Timeline\textsuperscript{10}

- **1950s-1960s**: Family-focused – with the family as a target of therapeutic interventions
- **1980s**: Family-centered care emerged with increasing recognition of the role of families in a child’s health and well-being
- **Mid 2000s**: Early models of wraparound promoted families as resources and partners; “family voice and choice” became a core principle
Family Movement in Children’s Behavioral Health

• Jane Knitzer: 1982
  • Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services
    • 2/3 of 3,000,000 children and adolescents with mental health (MH) concerns did not receive services OR received inappropriate care
    • Surveyed 50 states, outlined policy issues and state regulations leading to children falling through the cracks
    • Found the knowledge was there but no one was using it
    • Highlighted innovative programs and detailed steps for action to improve the system
Jane’s work kicked off decades of work to improve care for children.

(1) Family advocacy
(2) Focus on research
   a) Biological and social determinants of children’s MH concerns
(3) Prevention work
(4) Evidence-based treatments
2000’s

• By mid-2000’s “voice and choice” became a core principle and SAMHSA requested that mental health care be consumer and family-driven.

• “Family voice and choice” is one of the 10 principles of wraparound and is used, and understood by, the many stakeholders in the wraparound process in children’s mental health arena – now expanding into Peer Support and Recovery-Oriented Systems of Care – priority of Florida SAMH
<table>
<thead>
<tr>
<th></th>
<th>Family-focused</th>
<th>Family-centered</th>
<th>Family-driven</th>
</tr>
</thead>
<tbody>
<tr>
<td>View of family</td>
<td>Potentially part of “the problem”</td>
<td>Potentially part of “the solution”</td>
<td>Vital to improved health of children</td>
</tr>
<tr>
<td>Role of family</td>
<td>Object of therapy</td>
<td>Key informant on the child &amp; what works</td>
<td>Authority over the health care of their children</td>
</tr>
<tr>
<td>Decision making</td>
<td>Provider is primary decision maker</td>
<td>Family has input into decisions</td>
<td>Family makes informed choices</td>
</tr>
<tr>
<td>Outcomes - Family</td>
<td>Treatment adherence</td>
<td>Parent satisfaction</td>
<td>Parent empowerment &amp; increased skills</td>
</tr>
<tr>
<td>Outcomes - System</td>
<td>Improved relationship between family and provider</td>
<td>Increased transparency and coordination</td>
<td>Families become important cog in system improvement</td>
</tr>
</tbody>
</table>

Image: Davis, Et al.\textsuperscript{10}
Key Points:

• In *family centered*, the family makes decisions within the personal realm and provides its expertise to professional who continue to be responsible for professional or clinical decisions.

• In *family voice and choice*, the family is encouraged to lead the decision making but decisions are team based.

• In family-driven the family makes the decisions about their involvement and is supported by the team to make informed decisions.
Positives: 2008 Update

- Explosion of new knowledge and understanding of:
  - How children develop
  - How problems develop
- Explosion of new evidence-based programming
  - Prevention
  - Intervention
  - Medication
- Explosion of new evidence supporting family-centered care
What can we do?

We can take what we know works, family-driven care, and implement this in our daily practice.
Let’s Define:\(^3\):

- **Family-driven means:**
  - Families have the primary role in decisions regarding their children
  - Families have a role in policies and procedures governing well-being of children in their community, state, tribe, territory or nation
What does that look like? ³

• Strengths are identified
• Challenges are identified
• Families own desired outcomes and goals are identified, in their own words
  • And the steps to reach those goals are clear and understandable
• Families have help designing and implementing services for their child
• Families are able to monitor and evaluate services
• Families can choose supports, services, and providers who are culturally and linguistically responsive
It also means a full partnership in decision-making at all levels.
How do you do this?
Don’t think of yourself as the expert!

• Move away from the traditional model of the therapist being the expert. Rather, the family is regarded as the expert, and it is the therapist who listens to the family and is there to encourage and support the family and to guide the process.
You Say Potato…

When interacting with professionals, historically families have been approached from an “expert” model. Professionals often look at families from a clinical perspective and use clinical language. As you might imagine, this conveys to the family that they do not possess the resources they need to solve their problem and they require someone to solve it for them. The language that comes from the “expert” model significantly interferes with the ability of professionals and families to partner successfully in their families’ care.

Family Driven Care enables us to replace the language used in the “expert” model with language that will strengthen families and support them to make informed decisions for their children.

It seems like such a small thing to focus on, but when you realize that if you can change the way a person talks, you are one step closer to changing the way they think, you will then see the impact of a few small words.
Examples:

<table>
<thead>
<tr>
<th>The family will not comply with the plan</th>
<th>The family needs access, voice and ownership of their plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>The home is a disaster</td>
<td>The family needs support managing the home and establishing routine</td>
</tr>
<tr>
<td>The child is a sex offender/fire starter</td>
<td>The child has…behaviors</td>
</tr>
<tr>
<td>The family is not meeting their goals</td>
<td>The goals of the family appear to be challenging</td>
</tr>
<tr>
<td>The parents are adversarial</td>
<td>The parents are resilient and strong advocates</td>
</tr>
<tr>
<td>The parents need services</td>
<td>The parents have unmet needs</td>
</tr>
<tr>
<td>Client/case</td>
<td>Family/child</td>
</tr>
<tr>
<td>The family is chaotic</td>
<td>The family needs support in developing structure and routine</td>
</tr>
<tr>
<td>The child is explosive</td>
<td>The child is challenged with emotional regulation and distress tolerance skills</td>
</tr>
<tr>
<td>The child is unmanageable</td>
<td>The child needs support with distress tolerance</td>
</tr>
</tbody>
</table>
Expert Approach

Counselor

Family/Youth
Family-Driven

Counselor

Family/Youth
#1: Family is who you make it

- Families define their own family composition
- They choose who the decision-makers are
- Family can be:
  - Biological
  - Adoptive
  - Foster
  - Sibling
  - Surrogate voice acting on their behalf
How do you define family?

- **Genogram**\(^5\)
  - Often viewed as “just paperwork”
  - This is a family tree
  - Actually a very strong engagement tool that shows the family that you want to know them, you want to know their family, you want to know who the important people are in their life
Sociogram

• Tool for mapping social links within someone’s personal life. Ask a bunch of questions about their life, for example:
  • Who do you spend the most time with?
  • Who would you call if you needed a ride somewhere?
  • Who would you call if you needed money?
  • Who would you call if you were upset and needed someone to listen?

You put all of these people on the “map” and draw connections.
#2: Basic Access

Families and Youth:

• Have access to accurate, understandable and complete information necessary to set goals and make informed decisions

How do you make sure information is accurate and understandable?
How do you make sure information is accurate?

• Don’t assume anything
• Ask the family directly
• Document information in their own words
• Repeat it back to them to ensure it is correct
• Note who you learned the information from in case you ever need to go back to clarify such as “Per, mom’s report”; “Per the physician’s report”, “As noted in the file received from the probation office,”
• If you have to contact another agency or service ask yourself if the family can do it on their own with our assistance or if you can include them in the call.
How do you make sure information is understandable?

- **When possible write responses in client’s own words.** It is very powerful having the treatment goal written in your own words instead of someone else’s.

- **Write things down.** If the family has to complete a task have them write down what they need to do on a reminder sheet.

- **Avoid jargon.** What does that even mean?
  - Good rule of thumb is to write at the same level as the newspaper.
How do you help families make decisions once they have understandable and accurate information?
• Sit with the family and:
  • explain test results
  • explain paperwork (e.g. legal documents, school paperwork, treatment plan, consents)
  • explain procedures (e.g. how a referral will work, transfer, change in provider)
  • actually read the information together and answer questions

• Give the family:
  • time to review the information
  • time to feel supported with your presence and assistance
  • answers in a language and level they can understand
#3: Shared Decision-Making

- All stakeholders, including the family, meet to discuss and decide on desired outcomes
- When there is a disagreement:
  - Everyone comes together
  - Differing views are discussed
  - Through negotiation and conflict prevention a decision is reached
#4: Higher Level Changes

• Families invited to lend a voice to policies and procedures
• Agencies take the initiative to change from provider-driven to family-driven
• Time and resources set aside to seek funding to support family-driven care
• Celebrate diversity and eliminate disparities
• Remain responsive to the changing needs of the community
Examples of Higher Level Changes:

• You can find some specific examples here:

  Applying the Principles of Family-Drive Care at the Community Level
  https://docs.wixstatic.com/ugd/49bf42_df95a20954a444e0a86b1e1bdbb90739.pdf

• Programs, agencies, service providers, and organizations do regular cultural and linguistic evaluations and develop reports that outline their strengths, challenges, and progress from year to year.

• Businesses and programs identify community cultures and make efforts to learn about their customs and values. They use this information to ensure their materials and resources are relevant to those served.

• They utilize a family driven approach to hiring, recruiting, training, supporting, and evaluating those employed.
Are we there yet?

• Report from the University of South Florida (2007):

“This report is offered as a guide to assist in Florida’s continuing process of transforming the systems of care and support for families that have children with emotional and behavioral challenges into effective systems that are family-driven.”

https://docs.wixstatic.com/ugd/c345a4_92abb23b5a0f4b5f975fdcedcd12614b.pdf
How to set the tone

Engagement & Alignment
Engagement

- The family likes you
- They trust you
- They reach out for help
- Your interactions are positive
- They answer your calls
- Show up for sessions/meetings

Photo: Jaime Mulligan
Alignment

- Agree on goals
- Family follows through on homework/tasks
- Evidence recommended changes are being made
- Believe the treatment/service will help
How to gain Engagement and Alignment:

- Ask what the family needs
- Ask what they have already tried
- Ask what barriers they have faced
- Ask how they are doing
- Ask how you can support them
- Respect their unique situation
  - Acknowledge how tough this may be for them
- Explain how treatment/services will help
- If they do not follow through on something confirm the goal met their needs and that all barriers to success were removed
Losing Engagement and Alignment

• Decisions made without the family
• Family feels judged
• Family does not feel heard
• You have not considered the whole family
• Family concerns are not being taken seriously
• You show up late and/or change appointments
• You don’t remember the family’s story
• Making assumptions
• Being condescending
What to do if you are stuck:

• Complete a **Concept Map**
• Problem-solving tool you can use alone or in supervision to brainstorm why you are having problems with engagement, alignment, or any other issue impacting the family’s success
• You can even use this with the family to engage them in the problem-solving process!
What are some reasons why this is a good option in their world?

Well-Defined Problem goes in the middle

What is contributing to this problem (or positive!)

What is contributing to this problem (or positive!)

What is contributing to this problem (or positive!)
Did not get the job

Late to interview

Interview clothes were dirty

Mom called into work

No one else to give me a ride

Not sure how to prepare

Had to watch brother

I did not prep like I was supposed to

Saw someone there I don’t like

Grounded so could not use wash

Did not plan ahead enough

Used to smoke with him

Don’t want job if he works there
Practice Time!

Let’s complete a concept map together. What are some issues you run into that we should put in the center? Add them to the chat now...
5 Minutes

On your own, draw a map
Write in some ideas why this issues or concern may be happening
5 Minutes

On your own draw out a map.
Write in the reason why this issue/barrier is occurring.
Use a survey to gauge your success with giving the family a voice and a choice
Why do we need a survey?

• We can’t rely on ourselves to judge our effectiveness.
• We can’t deliberately “improve alliance”
• Instead, we need to ask the family how they feel about the service and adjust accordingly
• AND, as providers, the best thing we can do is improve listening, empathy, and positive language which will then improve alliance
Helping Alliance Questionnaire II (HAQ-II)\textsuperscript{8}

- Measure of perceived therapeutic alliance for both the counselor and the consumer of services
- 19 items
- Higher scores indicate a stronger alliance between the counselor and consumer
HAQ-II

• As a therapist uses more empathic language the relationship improves
• You will receive a PDF of this form
• It is an older survey so you can update the language to fit your needs. Just don’t change the content of the questions.
  • For example, you can change therapist to counselor, advocate, etc.
  • You can change therapy to wraparound, counseling, etc.
Let’s look at the survey...

• Things to ask yourself:
  • What can I do to raise scores on these items?
  • What can my agency do?
  • Is there anything our community can do?
**Instructions:** These are ways that a person may feel or behave in relation to another person—their therapist. Consider carefully your relationship with your therapist, and then mark each statement according to how strongly you agree or disagree. *Please mark every one.*

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Slightly Disagree</th>
<th>Slightly Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel I can depend upon the therapist.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2. I feel the therapist understands me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3. I feel the therapist wants me to achieve my goals.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4. At times I distrust the therapist’s judgment.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5. I feel I am working together with the therapist in a joint effort.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6. I believe we have similar ideas about the nature of my problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7. I generally respect the therapist’s views about me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
Working Alliance Inventory

- The Working Alliance Inventory-Short Revised (WAI-SR) is a measure of the therapeutic alliance that assesses three key aspects of the therapeutic alliance: (a) agreement on the tasks of therapy, (b) agreement on the goals of therapy and (c) development of an affective bond.
How to use the Working Alliance Inventory

• Counselor version
• Family version

• You complete the counselor version and family completes the family version
• Compare outcomes. If their scores vary widely then there is a disconnect
• Look at items that differ and work to improve your score by changing your approach
Let’s look at the survey...

• Things to ask yourself:
• What can I do to raise scores on these items?
• What can my agency do?
• Is there anything our community can do?
and I agree about the steps to be taken to improve his/her situation.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

2. My client and I both feel confident about the usefulness of our current activity in therapy.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

3. I believe ____________ likes me.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

4. I have doubts about what we are trying to accomplish in therapy.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

5. I am confident in my ability to help ____________.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

6. We are working towards mutually agreed upon goals.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

7. I appreciate ____________ as a person.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

8. We agree on what is important for ____________ to work on.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

9. ____________ and I have built a mutual trust.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

10. ____________ and I have different ideas on what his/her real problems are.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

11. We have established a good understanding between us of the kind of changes that would be good for ____________.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always

12. ____________ believes the way we are working with her/his problem is correct.

1. Never
2. Rarely
3. Occasionally
4. Sometimes
5. Often
6. Very Often
7. Always
1. _____________ and I agree about the things I will need to do in therapy to help improve my situation.

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
</table>

2. What I am doing in therapy gives me new ways of looking at my problem.

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
</table>

3. I believe _____________ likes me.

<table>
<thead>
<tr>
<th>Never</th>
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<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
</table>

4. _____________ does not understand what I am trying to accomplish in therapy.

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
</table>

5. I am confident in _____________ ’s ability to help me.

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
</table>

6. _____________ and I are working towards mutually agreed upon goals.

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
</table>

7. I feel that _____________ appreciates me.

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
<th>Always</th>
</tr>
</thead>
</table>
Take Home Points

• Our “systems” may not yet be fully family driven but that doesn’t mean we can’t be.

• You are no longer the expert. The family is the expert in their own lives. You guide them to solutions using your expertise and resources.

• If you get stuck complete a Concept Map.

• Maybe there is an engagement and alignment disconnect. Just because the family likes you does not mean they agree with what you are doing.

• Surveys are great! Use surveys to ensure you have a strong working alliance.
Resources

• National Federation of Families for Children’s Mental Health
  • www.ffcmh.org

• GenoPro: Free software you can download to help you create a genogram
  • www.genopro.com

• Family Engagement and Trust Building Skills Checklist, Vermont Federation of Families for Children’s Mental Health.
  • https://docs.wixstatic.com/ugd/c345a4_5f543391aeec46fdad888696fc0d4f86.pdf
Resources

• Helping Alliance Questionnaire (Hag-II): Downloadable forms. Family and therapist versions and scoring
  • [https://www.med.upenn.edu/cpr/instruments.html](https://www.med.upenn.edu/cpr/instruments.html)

• Working Alliance Inventory: Downloadable forms. Various versions in multiple languages.
References


