Family Journey Assessment (FJA)  
Parent Support Provider Training

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The Family Journey Assessment was developed through a collaboration between current and former staff of the Montgomery County Federation of Families for Children’s Mental Health (MCFOF) and the Georgetown University Center for Child and Human Development (GUCCHD)

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Training Goals

Learn about:
- FJA Background and Development
- FJA Administration

Practice FJA Scoring
- Videotaped Interview & Group Discussion

Practice FJA Administration
- Practice Interviews with partners

Discussion, Questions & Answers
Parent Support Providers (PSPs) provide support to families with children and youth with special needs. They help family members progress in their journey towards self-advocacy and self-efficacy through the acquisition of skills, knowledge and a network of support.
Family Support Model

- PSPs work with families to identify targets and benchmarks for focused and individualized family peer-to-peer support.

- PSPs provide peer-to-peer support that helps families resolve their own challenges and address their unique needs.

- Family members have the opportunity to become involved in local and state policy making.

- Some family members become advocates for their own children as well as for other children (Legacy stage).
A family member may fall in one of four stages on a family support continuum: intensive, moderate, supportive, and empowered.

The family member’s movement on this continuum is fluid. A family member may move back and forth from one stage to another.
Accountability

In a climate of results-based and outcome accountability, an emphasis on evidence-based practices, and a challenging fiscal climate, it is critical that family organizations measure:

- What they do
- How much they do
- How well they do it
- Outcomes - Is anyone better off?
Family Journey Assessment

The Family Journey Assessment:

- Is completed by parent support providers (PSPs) in collaboration with family members,
- Tracks family members’ progress in their journey towards self-advocacy and self-efficacy through the acquisition of skills, knowledge and a network of support,
- Provides indicators for the specific level and content of peer-to-peer skill-building and support depending on the stage the family member is in at a particular point in time.
Family Journey Assessment: Development

- Background and research on family-family support
- Steps in the development of the FJA
  - Key Outcomes
  - Item Creation
  - Administration
  - Scoring
Key Caregiver Outcomes

Derived from MCFOF family support experience and those of others:

- Self knowledge (e.g., communicates needs, accepts and appreciates strengths and challenges of self and child)
- Well-being and reduced self-blame (e.g., family relations and decision making, daily routines)
- Knowledge seeking (e.g., resources, systems)
- Collaboration and connection to decrease isolation (e.g., stakeholders, natural supports)
- Use of knowledge (e.g., communicate, discuss, involvement)
Key Caregiver Outcomes

Derived from MCFOF family support experience and those of others*

– Coping (e.g., self-efficacy, problem-solving, self-care)
– Increased activation to gain knowledge and become actively engaged in child’s care and services
– Advocacy

What Does Research Tell Us About Providing Family Support?

Most on clinician-delivered family support

- Improves activation in seeking care
- Improves self-efficacy - active participation in decision making
- Improves knowledge and understanding of children’s mental health (associated with utilization of higher quality services for children)
- Improves knowledge, retention, satisfaction with care, health outcomes, and receipt of appropriate treatments for children
- Evidence unclear as to whether or when family-based services actually improve child outcomes
What Does Research Tell Us About Providing Family Support?

Targeted attention to family-focused outcomes is needed!!!
Differences with Other Measures

- Developed directly from experiences of FSPs and goals of family support—important movement, process and experience of family journey.

- Comprehensive

- Less about satisfaction with youth’s progress and related services

- Specific skills and knowledge

- Focuses on progress that would reduce the impact of caregiving burden: working with others, problem solving, coping and implementation of gained knowledge and skills
Steps in FJA Development

- Began with a clear conceptualization of the target outcomes
- Creation of initial item pool
- Modification of pool
- Item pool/structure tested with initial small sample of PSPs
- Larger scale testing of reliability and validity (in progress!)
Creation of FJA Item Pool

- Item Development
  - Year-long, iterative process
  - Attention to item wording; item modification

- Initial Evaluation
  - Created and scored vignettes
  - Grouped items in content clusters
  - Separated Legacy items

- Feasibility of Administration
  - Implemented by MCFOF staff
  - Administration guidelines developed from feedback

- Wraparound Scale development
FJA Components

- Basic Scale – 36 items, 6 clusters
  - Core set of items used to assess progress of caregivers relevant to a range of support situations

- Wraparound Scale – 20 items
  - An additional set of items to be used to assess caregiver’s attainment of goals specific to their involvement in the Wraparound service delivery process

- Legacy Scale – 8 items (in development)
  - An additional set of items to be used to assess a caregiver’s involvement in advocacy activities for other families with children with special needs and/or to provide support for these families.
Family Journey Assessment: Rating Scale Based on Level of PSP Assistance Needed

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<tr>
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<th>Moderate</th>
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The family member finds it very difficult to make changes to improve the current situation; requires active intervention from FSP.

The family member needs extensive assistance and encouragement from FSP to make changes necessary to improve the current situation.

The family member needs limited assistance from FSP to make changes necessary to improve the current situation.

The family member is making changes to improve the current situation without assistance from FSP.
Cluster 1: Self-Knowledge (9 items)

Items in this cluster tap the caregiver’s capacity to recognize and realistically communicate the strengths and needs of their child and their own strengths and needs and to see the importance of this process.

Cluster 2: Family Well-Being (5 items)

This cluster includes items related to the caregiver’s involvement in interactions within and outside of the family that involve making decisions affecting the family and child, to his or her feelings of support and connections within and outside the family, and to the family’s ability to maintain a daily routine.
Family Journey Assessment: Item Clusters

- **Cluster 3: Seeking Information (2 items)**
  The two items in this cluster concern the caregiver’s efforts to obtain resources relevant to helping the child or youth, such as information about relevant systems and other available community resources.

- **Cluster 4: Collaborates with Others (6 items)**
  Items in this cluster tap whether caregivers access help from formal supports, natural supports, and those who have had similar experiences.
Family Journey Assessment: Item Clusters

Cluster 5: Owns Newly Attained Knowledge (6 items)

Items in this cluster assess caregiver use of information and skills gained to address the needs of the youth and family, including effective communication (e.g., active participation, assertiveness), advocacy and recruitment of support.

Cluster 6: Coping Skills (8 items)

Items in this cluster assess whether the caregiver has been able to develop and carry out a plan to address stressors and handle crises. Items also examine the ability to understand and handle feelings of distress to further resilience and perseverance.
FJA Wraparound Subscale

Wraparound Subscale (20 items)

This subscale can be administered when families are participating in a wraparound process that follows established principles and procedures specified by the National Wraparound Initiative. The wraparound items of the FJA are derived from work specifying the application of wraparound principles to the role of FSPs on wraparound teams (Penn & Osher, 2008).
FJA Legacy Subscale

Legacy Subscale (8 items)

The items in this subscale can be used to track the journey of families who have moved into a “legacy” stage—the evolution of caregivers who have been recipients of family support into providers of such support. The items tap key aspects of advocacy for others, including comfort in sharing their “story” and the principles of the family movement, connecting with families with similar experiences and helping them find and use supports, and actively participating in more formal experiences (e.g., leadership training, committees, conferences, legislative sessions).
FJA Administration

Administered by the family support provider in collaboration with the family member
- A way to help track the progress of their work together
- Clusters link to key purposes of family support (information, advocacy, support, coping, collaboration)

Baseline
- Within 2 weeks of the beginning of involvement
- Used in a discussion of the goals of family support

Follow-up
- Three month intervals/end of service
- Introduced in the context of reviewing the progress that the family has achieved since the last administration

Celebrate success
Cover Page

Very important!!

Fill out the cover page for every administration of the FJA.

It is important to keep track of the caregiver, family, and rater (PSP) ID numbers.

The “comments” lines should be used to note important contextual factors (e.g., level of involvement, affect, recent events) that might influence the results.
Administration

- Semi-structured interview format (see Administration Prompts handout):
  - Begin with general open-ended questions organized around the clusters.
  - Follow up with prompts if necessary.
  - The interviewer needs a good understanding of the test items and experience in conducting this type of interview.

Feedback: Check your impressions with the family member and reconcile differences (See Administrative Prompts handout).

Throughout the interview, it is important to remember to remain as open and non-judgmental as possible.
Example of Administration Format: Self Knowledge

General Prompts

- *Tell me about how things are going with (child’s name)?*
- *What do you think would really help (child’s name)?*
- *How easy is it for you to talk with others about (child’s name)? What helps?*
- *Tell me about how things are going with you.*

Specific Prompts

- *Let’s talk about what has caused (child’s name) difficulties?*
- *What are some of the good things that people might say about (child’s name)?*
- *How do you think you and your family can help with (child’s name) difficulties?*

Specific item can be read (or paraphrased) to the family. This should be the last resort.
Rating Guidelines

- The FSP should integrate their current knowledge of the family; information provided by the family during the FJA interview discussion; other conversations with the family; observation; and information from the youth, natural and formal supports, and other key stakeholders.

- Ratings should reflect the family’s average level of functioning for each item during the past month.

- Use observation and reported information in making a rating. Try not to use what you “think” the caregiver’s skills or knowledge are.

- Expect that there will be fluctuations—may not be a linear process.
Rating Guidelines

- Take into consideration factors such as gender, life experiences, cultural heritages, socio-economic circumstances and beliefs/values.
- Try not to impose your own value judgments that may be heavily influenced by your age, gender, social class, or cultural background.
- Always work with the family when using this tool – it is a dialogue.
- Try to use the same procedures for gathering information (e.g., talk to the same informants, use the same interview format) for each administration.
## Anchors

### Cluster 1: Self-Knowledge

Communicates needs related to culture, language, learning and thinking styles in order to progress

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<td>The caregiver is unable to or does not articulate beliefs or expectations or verbalize information that is necessary to address the child’s needs. He is not aware of the family’s, and particularly the child’s, needs and is unaware of personal thinking and learning styles. The caregiver may feel intimidated by professionals or may be unable to communicate in the English language.</td>
<td>The caregiver communicates limited information about the family and the child’s needs. His ability or willingness to communicate needs may differ based on who he is communicating with. Needs are communicated with little explanation or rationale.</td>
<td>The caregiver communicates most needs to most people who need to be informed. His ability or willingness to communicate needs may differ based on the sense of comfort/connection with the person he is communicating with.</td>
<td>The caregiver is very aware of the needs of the family and child and effectively communicates and verbalizes his needs to those who need it.</td>
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Example
Cluster 1: Self-Knowledge
Communicates needs related to culture, language, learning and thinking styles in order to progress

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<td>Mr. Conteh, who is of West African descent, has strong religious/cultural beliefs that conflict with the use of psychiatric medications. When his son’s pediatrician suggests the use of stimulant medication for ADHD, he takes the prescription but never fills it.</td>
<td>Mr. Conteh tells his son’s doctor that he does not want his son to take stimulant medicine because he “knows it won’t work”. Although the pediatrician suggests alternative medications, Mr. Conteh refuses to consider them.</td>
<td>Mr. Conteh tells his son’s doctor that he does not believe in medication, but does not elaborate. He does ask for alternative treatments. He is able to talk with the family support provider about his religious concerns.</td>
<td>Mr. Conteh explains to his son’s doctor that psychiatric medications are against his beliefs. He gives examples of the treatments that he would be willing to consider. He asks the pediatrician about other options to improve his son’s focus and reduce hyperactivity</td>
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Example of Feedback Format: Self Knowledge

- It sounds like you have a great sense of what (child’s name) needs to succeed. Maybe you are focusing so much on her needs that you have difficulty making time to take care of yourself. What do you think?

- We talked (child’s name)’s strengths, challenges, and needs. You explained his needs very clearly. Do you think that you are able to recognize and communicate his strengths and challenges in the same way?
Next Steps in Evaluation

Administration of the FJA to further explore

- Reliability
- Construct validity (factor structure of clusters, relationship to other measures)
- Sensitivity to change
## FJA Feasibility Survey

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<th>5</th>
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<tbody>
<tr>
<td>Understandable</td>
<td>Very difficulty to understand</td>
<td>Difficulty to understand</td>
<td>Neither difficult nor easy to understand</td>
<td>Easy to understand</td>
<td>Very easy to understand</td>
</tr>
<tr>
<td>Ease of Response</td>
<td>Very difficulty to respond</td>
<td>Difficulty to respond</td>
<td>Neither difficult nor easy to respond</td>
<td>Easy to respond</td>
<td>Very easy to respond</td>
</tr>
<tr>
<td>Relevant</td>
<td>Not at all relevant/does not apply to family journey</td>
<td>A little relevant/appplies a little to family journey</td>
<td>Somewhat relevant/somewhat applies to family journey</td>
<td>Relevant/does apply to family journey</td>
<td>Very relevant/applies very much to family journey</td>
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Parents/Caregivers Views of FJA

- Keeps focus on goals
- Better understanding of the systems
- Decrease sense of feeling overwhelmed and operating from crisis mode
- Greater sense of self-efficacy
- Know how to make changes