

The Family Journey Assessment: Tracking the Impact of Family Support



Presented by

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Goals

- **Conceptual Framework:**
 - How the FJA's content has been informed by the experiences of family members who have experienced the journey and provided support to other families.
- **Development**
 - Item creation, including its relation to other measures, and its current structure and administration
- **Examples**
 - Illustrate how the FJA can help family support partners and family navigators provide a specific level of peer-to-peer support, identify strategies to engage families in the treatment process, develop specific interventions for the plan of care, and assess

Family Organization

- **The Montgomery County Federation of Families for Children's Mental Health is non-profit organization run by family members who have children with emotional, behavioral, or mental health challenges.**
- **We help other family members who are raising children with similar challenges.**



Family Program Staff

- They are family members who have children with emotional, behavioral, or mental health needs.
- They are skilled and knowledgeable family members who provide direct services to parents and other primary caregivers who have children with similar challenges.
 - peer-to-peer support
 - information and referral
 - advocacy
 - group support
 - educational programs
 - leadership opportunities



Passing the Baton: Building Leadership From Within

Several employees were recipients of services from the family organization before becoming staff.

All staff work to promote the evolution of legacy family members.



Job Functions

- Family Support Partner
 - Works primarily with family members enrolled in wraparound.
 - Promote family member's full engagement and participation in all phases of wraparound.
 - Play a role in promoting wraparound principles.
- Family Navigator
 - Works with family members who have children with special needs.
- Parent Engagement Coordinator
 - Works with family members whose children are involved, or at risk of involvement, in the juvenile justice system.



The Ten Principles of Wraparound

The Family Support Partner plays an important role in implementing the wraparound principles:

1. Family Voice and Choice
2. Team-Based
3. Natural Supports
4. Collaboration
5. Community-Based
6. Culturally Competent
7. Individualized
8. Strength-based
9. Persistence
10. Outcome-based

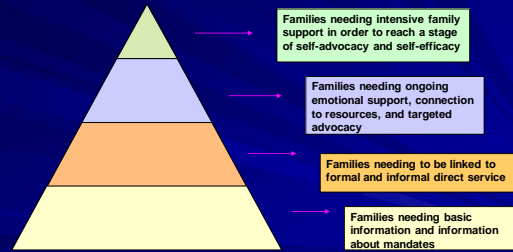


Family Support Model

- The staff work with families to identify targets and benchmarks for focused and individualized family peer-to-peer support.
- The staff provide peer-to-peer support that helps families resolve their own challenges and address their unique needs, while moving them to a legacy stage where they assist other families with similar issues.
- Family members have the opportunity to become involved in local and state policy making.
- In this model, family members become advocates for their own children as well as for other children.



Levels of Needs of Families Receiving Family Support



The Family's Journey

The Family Support Partners, Family Navigators, and the Parent Engagement Coordinator help family members progress in their journey towards self-advocacy and self-efficacy through the acquisition of skills, knowledge and a network of support.



Mapping the Journey





Milestones: Identifying and Tracking a Family's Journey

- Barry Kibel 's Outcome Engineering/Journey Mapping
- Marlene Penn's and Trina Osher's work on family partners in systems of care and wraparound
- Marlene Penn's "A Family's Journey Along the Way to Self-Advocacy"
- Jane Adams - Kansas Keys for Networking, Inc.'s Targeted Parent Assistance
- Richard Donner – skills for family support partners
- Patricia Miles – training for parent partners

SELF-EFFICACY

"Self-efficacy is the *belief* in one's capabilities to organize and execute the sources of action required to manage prospective situations."

Bandura, 1986

What Happens on the Journey?

Stages of Growth

The Federation staff promote a family member's movement along three primary stages in the growth process:

- Preparing for action – A family member is preparing to take specific action to improve his/her situation.
- Actions and successes – A family member has taken different actions and has experienced successes.
- Establishing a legacy – A family member is now moving to a legacy stage whereby he/she chooses to advocate for other family members having similar experiences and/or to provide support for these families.

Family Support Levels

A family member may fall in one of five stages on a family support continuum: intensive, moderate, supportive, maintenance, or legacy.

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



When providing peer-to-peer support, staff work in partnership with family members to determine where they are in their journey toward self-efficacy and self-advocacy and how they are progressing. The Family Journey Assessment identifies the baseline and helps to track the journey.

The Federation staff provide a specific level of peer-to-peer support depending on the stage the family member is in at a particular point in time.



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/How much they do
- * How well they do it
- * Is anyone better off

Family Journey Assessment: Development

- Research on family-family support
- Steps in the development of the FJA
 - Constructs
 - Item creation
 - Testing

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
- Reduces stigma and distrust by improving communication
- Improves knowledge and accurate beliefs about children's mental health (associated with utilization of higher quality services for children)
- Improves knowledge, retention, satisfaction with care, health outcomes, receipt of appropriate treatments

What Does Research Tell Us About Providing Family Support?

- Evidence unclear as to whether or when family-based services actually improve child outcomes
- Linkage of effective family-based services to effective child-focused services will likely amplify positive effects
- **Targeted attention to family-focused outcomes is needed**

Steps in Scale Development

- Begin with a clear conceptualization of the target constructs. Key, initial step in developing construct validity
- Creation of initial item pool
- Modification of pool
- Item pool/structure tested (iterative) with initial sample (relatively small)
- Larger scale testing of reliability and validity

Conception of Constructs

- Creating a formal description of the constructs

Journey (continuum) towards self-advocacy and self-efficacy through the acquisition of skills, knowledge and a network of support.

- Literature review
 - Previous attempts to conceptualize and assess both the same construct and closely related constructs.
 - Examine instruments from which the target is to be distinguished.

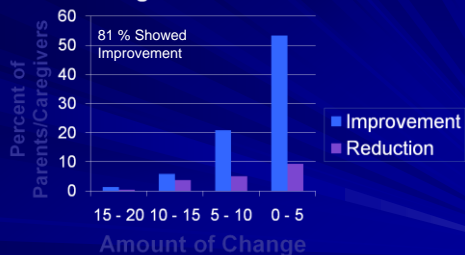
Other Measures of Family Journey

- Family Empowerment Scale
- Parent Empowerment Scale
- New York Outcomes Study
 - Based on Kible's work
 - Parent Empowerment Program
 - Brief stuff about this
 - Tracking work that parent advisors are doing
 - Changes in needs and strengths of families
 - FANS: Combination of caregiver scales from different CANS assessments (Family organizations in Western NYS, led by Nancy Craig in collaboration with John Lyons)

FANS: 15 Items

- Knowledge of needs
- Knowledge of rights and responsibilities
- Knowledge of service options
- Satisfaction with youths' living arrangements
- Satisfaction with youth's educational arrangements
- Social Resources
- Involvement
- Satisfaction with school participation
- Satisfaction with current services
- Listening ability
- Communication ability
- Organizational skills
- Talents and interests
- Recreation
- Optimism

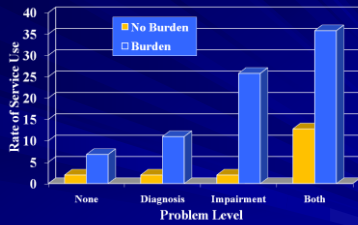
Percent of Caregivers Showing Change in Total FANS Score



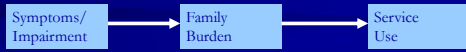
Motivation for FJA

- Create a measure with items of relevance to the important movement, process and experience of family journey.
- Key outcomes derived from family support experience
 - Activation (pursue options, something I can do)
 - Collaboration/Decision making
 - Advocacy
 - Self-efficacy
 - Caregiver Impact

Effect of Caretaker Burden on Service Use



Angold et al., 1998



Creation of FJA Item Pool

- Wanted to be overinclusive
- Item wording needed careful attention (simple, straightforward)
- Subscales identified
- Iterative process involving several periods of item writing and modification. Modified some conceptual structure
- Format choice

Family Journey Assessment: Item Clusters

- **Cluster 1: Self-Knowledge**
 - Communicates needs related to culture, language, learning and thinking styles in order to progress
 - Accepts and appreciates child's challenges
- **Cluster 2: Family Well-Being**
 - Develops and maintains a daily routine
 - Can contribute to the decision-making process around the child's issues

Family Journey Assessment: Item Clusters

- **Cluster 3: Seeking Information**
 - Seeks and uses help, resources, information, and materials
 - Has knowledge of child-serving systems
- **Cluster 4: Collaborates with Others**
 - Shows/demonstrates empathy for others
 - Accesses desired natural supports

Family Journey Assessment: Item Clusters

- **Cluster 5: Owns Newly Attained Knowledge**
 - Attends, participates in, and speaks up during meetings
 - Connects with families having similar experiences
- **Cluster 6: Coping Skills**
 - Understands the need to respond to own needs and looks for ways to take care of self
 - Handles crises, develops and carries out a plan

Family Journey Assessment: Rating Scale

Intensive	Moderate	Supportive	Maintenance	Legacy
1	2	3	4	5
Rarely, lacks, or does not have resources; needs support from FSP or FN in these areas to improve current situation.	With encouragement from FSP or FN, the family member is making changes to improve current situation.	With limited assistance from FSP or FN, family member is making changes necessary to improve current situation.	Without assistance from FSP or FN, family member is making changes to improve current situation.	Shows other family members how access resources and supports by sharing what they have learned.

Anchors: Communicates needs related to culture, language, learning and thinking styles

Intensive

- Difficult to communicate in the dominant language; rarely verbalizes information that is necessary to address needs; not aware of personal thinking styles, feels intimidated by professionals, difficulty communicating the family's, and particularly, the child's needs; has difficulty articulating beliefs or expectations, does not connect to community resources.

Maintenance

- Communicates and verbalizes his or her needs; actively seeks support, seeks educational opportunities (e.g., workshops), and peer to peer support. Very aware of the needs of the family and the child, seeks out community resources, already connected to natural supports, is able to seek and connect to new supports and resources.

Administration

- Administered by the family support staff in collaboration with the family members.
 - A way to help track the progress of their work together
- Semi-structured interview format
 - Begin with general open-ended questions
 - Suggested follow-up prompts
 - Interviewer needs a thorough understanding of the test items and experience in conducting this type of interview.
- Baseline and three month intervals/end of service
- Consider "average" of past month (?)

Administration

- Celebrate the success
- Expect that there will be fluctuations—may not be a linear process
- Take into consideration factors such as
 - Gender
 - Life experiences;
 - Cultural heritage;
 - Socio-economic circumstances;
 - Role models;
 - Beliefs/values.

Item/Scale Evaluation

- Multiple raters of standard vignettes
 - Calculated the average percent agreement for each item
 - For those items with low agreement, discussed ratings, adapted/deleted/added
- Administration of preliminary item pool to determine
 - Reliability internal consistency
 - Construct validity (factor structure of clusters, relationship to other measures)

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

Examples of Use of FJA in Family Support