Indicators of Meaningful Family Involvement

A Brief Guide for Individuals Looking to Understand How Meaningful Family Involvement Is Measured

NATIONAL FEDERATION OF FAMILIES
For Children's Mental Health ®

INTRODUCTION

Collaboration is the cornerstone of an effective child-serving system. At the heart of this collaborative partnership are the child and their family. This type of partnership that is wholly inclusive of the goals and desires of the child and their family is often referred to as "family-driven care".

Family-drive care is a core concept in the System of Care principles. Family voice determines family-driven care, as families must be central in creating this dynamic. The principles of family-driven care should inform all aspects of the practice of child-serving systems.

In 2002, President Bush appointed both the President's Commission on Excellence in Special Education and the New Freedom Commission on Mental Health. These two Presidential Commissions clearly support the opinion that parental involvement must progress to the point where families determine the nature of educational and social services for their children. The 2002 report "A New Era: Revitalizing Special Education for Children and Their Families"[1] emphasized the need for increased family involvement in the educational lives of their children and highlighted a need for parents to be integral partners in the design of educational programs.

Family-driven care was explicitly named and further emphasized in "Achieving the Promise: Transforming Mental Health Care in America" (2003)[2], the report of the President's New Freedom Commission on Mental Health, which was "designed to advance the community-based service delivery system built on efficiency and demonstrably effective practices."

The findings and recommendations included in both reports complement the need for family involvement as summarized in the following statement from the National Federation of Families for Children's Mental Health:[3]

"Families, youth consumers, and family oriented practitioners echo the findings and recommendations of the President's New Freedom Commission. They know that outcomes are better when families have a key voice in decision-making. Families know what works for them. Therefore, it makes sense that they drive service delivery decisions. Their experience is holistic. In other words, they do not have a mental health part, a child welfare part, a juvenile justice part, and so forth. Families focus on the concrete challenges that they face all day and every day. Families also know their strengths and their limitations. Families know the difficulties they face. Families can see change in how they or their child are doing on a daily basis. They know how a program, agency or system works (or doesn't work) for them. Most importantly, without family comfort and buy-in, children and youth won't participate in services. Also, family voices are listened to by politicians and public officials. Their passion and persistence are necessary to transform mental health services."

Included in *Shifting Gears: The Ambassador's Guide to Family Driven Care,* the National Federation of Families for Children's Mental Health defines "family-driven" as: Families have a primary decision-making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

- Choosing supports, services, and providers;
- Setting goals;
- Designing and implementing programs;
- Monitoring outcomes;

[1] President's Commission on Excellence in Special Education, (2002). *A new era: Revitalizing special education.* Retrieved September 15, 2014, from http://www.ed.gov/inits/commissionboards/whspecialeducation/index.html
[2] President's New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America. Final report* (DHHS Publication No. SMA-03-3832). Rockville, MD: U.S. Department of Health and Human Services
[3] Osher TA, Blau GM, Osher DM, (2006) *Shifting Gears: The Ambassador's Guide to Family Driven Care* [CD]. Rockville, MD: Federation of Families for Children's Mental Health.

- Partnering in funding decisions; and
- Determining the effectiveness of all efforts to promote the mental health and well being of children and youth

These principles were endorsed by the Institute of Medicine (IOM) in the "new rules" for a 21st century health care system:[4]

- Care is based on continuous healing relationships (most notably, family relationships)
- Care is customized according to (youth and family) needs and values
- The patient (family of the patient) is the source of control
- Knowledge is shared and information flows freely
- Transparency is necessary

In 2009, the American Academy of Child and Adolescent Psychiatry (AACAP) released a policy statement, "Family and Youth Participation in Clinical Decision Making" that included the following components:[5]

- Family and youth involvement is essential at each phase of the treatment process, including assessment, treatment planning, implementation, monitoring, and outcome evaluation.
- Family and youth partnership also needs to inform decision making at the policy and systems level.
- Family priorities and resources must be identified and should drive care.
- Throughout the treatment process families and youth must:

  - have the right to be involved in making decisions regarding providers and others involved in the treatment team;
  - be encouraged to express preferences, needs, priorities, and disagreements;
  - collaborate actively in treatment plan development and in identifying desired goals and outcomes;
  - be given the best knowledge and information to make decisions;
  - make joint decisions with their treatment team; and
  - participate actively in monitoring treatment outcomes and modifying treatment.

The education system has long voiced strong support for active family participation in the education of children with exceptional challenges. The Individuals with Disabilities Education Act (IDEA) was first signed into law in 1975 as the Education for All Handicapped Children Act (PL 94-142). This law has been amended on multiple occasions and was designed to provide guidelines for the provision of special education services to students with disabilities, ensuring that these students are provided with a free and appropriate public education. The law addresses the rights of special education students and their parents. IDEA requires active involvement of parents as members of their child's educational team, including encouraging parents to invite persons of their choosing to a meeting regarding their child.

The concepts of family-driven and family involvement are not new, however there continues to be a lag in transformation in many child-serving systems (e.g., mental health, education, juvenile justice, intellectual disabilities). To achieve a transformational effect, it is incumbent upon all systems to be well-versed in the Federal initiatives and legislative efforts that address children and their families. While attitudinal change cannot be legislated, family-friendly legislative efforts can promote organizational policy and cultural reassessment that often leads to change.

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[4] Institute of Medicine. (2001) Formulating new rules to redesign and improve care. In: *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC.: National Academy Press; 61 – 89.
[5] American Academy of Child and Adolescent Psychiatry. (2009). *Family and Youth Participation in Clinical Decision Making.* Retrieved September 15, 2014 from
http://www.aacap.org/cs/root/policy_statements/family_and_youth_participation_in_clinical_decisionmaking

Child-serving systems experience the paradox of ever-evolving, evidence based/supported practices that are mired in a landscape of stagnation. While the field continues to develop and implement cutting edge treatments, many communities continue to experience an uneasy tension amongst families and professionals. This tension is exacerbated by institutional requirements (insurance regulations, etc) that often do not support proactive solutions for children and their families. As former Senator Patrick Kennedy remarked, "If insurance regulations were the same for the treatment of cancer as they are for the treatment of mental illness, patients would be told to return for treatment when their cancer reaches stage 4."[6]

To fully embrace the concepts of family-driven services and supports is a complex, multidimensional effort. Osher, Osher, and Blau (2006) offer the following principles to effect the exponential change that is required to recreate current systems. For purposes of these principles, "family-run" organizations are defined as organizations that are governed by families who have the lived experience of having parented a child with social, emotional, or behavioral challenges.

- Families and youth are given accurate, understandable and complete information necessary to set goals and to make choices for improved planning for individual children and their families
- Families, youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes
- Families and youth are organized to collectively use their knowledge and skills as a force for systems transformation
- Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information and strengthen the family voice
- Families and family-run organizations provide direction for decisions that impact funding for services, treatments and supports
- Providers take the initiative to change practice from provider-driven to family-driven
- Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth and families
- Community attitude change efforts focus on removing barriers and discrimination created by stigma
- Communities embrace, value and celebrate the diverse cultures of their children, youth and families
- Everyone who connects with children, youth and families continually advances their own cultural and linguistic responsiveness as the population served changes

Measuring meaningful family involvement requires a multifaceted approach. Due to the qualitative nature of this measurement, simply counting the number of families present at a meeting will not suffice. It is the level of participation, the intensity of the collaborations, and quality of the partnerships that are the critical variables.

Family involvement can occur at several levels. Three levels will be discussed here: Individual, practice, and system:

- "Individual" is defined as those matters that directly impact the life of the child and   his/her family
- "Practice" is defined as services and supports that are created and implemented on behalf of the child and their family
- "System" is defined as the governance structure, management, operations and evaluation at the local, state and national level

While "involvement" is a concept that is difficult to quantify, the following definitions are offered:

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[6] Kennedy, P. (2014, September) *Opening Legislative Plenary.* Speech presented at the National Alliance for Mental Illness National Convention, Washington, DC.

- Indicator – a measure or gauge of a state or level
- Meaningful – significant, purposeful, valued
- Participation – the act of taking part or sharing
- Passive Involvement – the act of observing or supporting the actions or others (spectator)
- Active Involvement – the act of engaging in the actions that are occurring (participant)

Equally important is our understanding of why families may not choose to be involved or why they may not feel that they are meaningful participants. There are multiple factors that may inhibit a family's willingness to actively participate. Let's consider possible reasons why families are reluctant to engage:

- Parents feel overwhelmed and isolated by lack of information
- Parents feel intimidated by an unequal power structure
- Parents feel the stigma of blame and a lack of respect

When asked to describe elements that enhance the level of comfort and support needed to create meaningful partnerships, families are extremely forthcoming about factors that increase positive outcomes. These include:

- Balanced relationships and interactions
- An atmosphere of acceptance and respect
- An explanation of jargon
- A culture of "team" with multiple systems actively working in a collaborative fashion

This level of support is well described by the National Federation of Families for Children's Mental Health. "Family support" is describes the specific contributions of youth and family members in child-serving systems where family-driven practice occurs. It is defined as follows:[7]

"Family support is a constellation of formal and informal services and tangible goods that are defined and determined by families. It is "whatever it takes" for a family to care for and live with a child or adolescent who has an emotional, behavioral or mental disorder. It also includes supports needed to assist families to maintain close involvement with their children who are in out-of-home placement and to help families when their children are ready to return home."

INDICATORS OF MEANINGFUL FAMILY INVOLVEMENT

ASSUMPTION	INDICATORS
INDIVIDUAL: Family is fully participatory as partners in decision-making about their child's services and supports	- Families select participants for all planning activities - Families are fully involved in decisions involving treatment modalities - Families are availed the opportunity to select providers and staff - Families create schedules with all providers to facilitate smooth family routines - Families are empowered to change services, supports, providers or staff when deemed in the best interest of their child

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[7] Federation of Families for Children's Mental Health (1992). *Principles on Family Support.* Retrieved September, 2014 from http://www.ffcmh.org

	• Families are given full information about their rights and the rights of their child

ASSUMPTION	INDICATORS
PROGRAM/PRACTICE: A commitment to "nothing about us without us" is evidenced throughout all planning and decision-making processes as related to services and supports on behalf of the child and their family.	• Meeting times are scheduled in accordance with the schedules of the family • Planning does not occur without the family present • Accommodations are made to assist with ancillary supports such as transportation, child care, respite • All team members are respectful of the cultural and linguistic uniqueness of each family • Meeting facilitation is a shared responsibility and all team members are accountable for the outcome
Services and supports are designed to reflect evidence-supported, person-centered principles	• Families receive thorough information about services, supports and treatment modalities regardless of whether or not they are a part of the current array of available • Services and supports are designed to meet the goals and desires of the child and their family • Natural supports are of the highest priority in the planning process • Families are empowered to select or reject potential providers • Families are encouraged to connect with supports such as peer supports and support groups
Professional and experiential expertise complement one another	• Decisions are based upon the family's preferences, choices and values rather than administrative expediencies • Families have access to a flexible, affordable, person-centered array of supports and services that are designed to enhance the family structure • Families experience authentic caring and respect in all interactions with professionals • All team members follow through on agreements reached collaboratively • Families respect the professional's knowledge and experience • All team members are open to the identification and utilization of non-professional (natural) sources of support
ASSUMPTION	INDICATORS
GOVERNANCE: All levels of governance of the child-serving system actively engages family participation	• Families are equitably represented in governance structures • Families participate on committees, workgroups, and other decision making groups • Policies are in place and adhered to that require family participation in the governance process

	• Strategies are implemented to ensure that governance is culturally and linguistically competent • Governance meetings are scheduled to reasonably accommodate the schedules of families • Families are offered compensation and support for participation
ASSUMPTION	**INDICATORS**
MANAGEMENT/OPERATIONS: Management, policies and procedures reflect a "family friendly" attitude	• Families participate equitably in the development of policies and procedures. • Staffing structures include individuals with lived experience • Staffing structures reflect the cultural and linguistic demographics of the community • Cultural, language, and lifestyle preferences are reflected in the service and support array.
ASSUMPTION	**INDICATORS**
EVALUATION: The evaluation of programs, policies and systems includes a strong family voice.	• Information on family outcomes is used to improve services and supports • Information on families' experiences with the service delivery process is used to improve services • Families are involved in the quality monitoring process (e.g. help choose indicators to be monitored, help develop studies, participate in data collection process, participate in reporting findings to stakeholders)

As indicators are established and measured, it is important that systems determine which entities are demonstrating meaningful family involvement. Through this process, those attitudes, mechanisms and strategies that are creating partnerships with families and empowering the family voice will emerge. To facilitate cultural change that results in meaningful family involvement, Osher and colleagues (2006) propose the following examples:

- Ensure that meetings occur at times that are realistic for families to attend;
- Conduct meetings in culturally and linguistically competent environments;
- Ensure that family and youth voices are heard and values;
- Ensure that families and youth have access to useful, usable and understandable information and data;
- Provide sound professional expertise to help families make decisions;
- Share power, authority, resources and responsibility; and
- Construct funding mechanisms to allow families and youth to have choice

As local, state, and national systems continue to move forward to embrace the concepts and values of family-driven care, child-serving agencies will experience a paradigm shift in service delivery systems:[8]

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[8] Osher TA and Osher D. The paradigm shift to true collaboration with families. *J Child and Family Studies,* 2002; 11:47-60

	PROVIDER DRIVEN	FAMILY DRIVEN
Source of Expertise	Professionals and agencies	Child, family and network
Relationship	Child and family viewed as a dependent client expected to carry out instructions	Partner/collaborator in decision making, service provision and accountability
Orientation	Isolating and "fixing" a problem viewed 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	Agency resource based	Individualized for each child and family
Access to Services	Limited by agency's menus, funding streams, 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

Implementation of these concepts will require an evolution in many of our child-serving systems. While this transformation will not occur overnight, there is a compelling body of literature that suggests that children thrive in systems that are welcoming, inclusive and respectful of the meaningful involvement of families at every level.