Family/Parent Partners
Making Family-Driven Care
Work in the Real World

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Purpose

This discussion will trace the transformation of the family involvement leading to the definition of family-driven care and the development of procedures and tools, such as the Ambassador’s Guide to Family-driven Care and the National Wraparound Initiative’s specification of the family/parent partner role, to insure its implementation with fidelity on a broad scale.

Finding the Definition for Family-Driven

• Expert professional and family panel – culturally diverse, different perspectives, and geographically distributed;
• Interviews with recognized leaders in the family movement;
• Open forum discussions held at training institutes and conferences;
• Literature review conducted;
• Feedback solicited from system of care communities and family-run organizations; and
• Reactions gathered at presentations like this one.

Definition of Family Driven Care

Family-driven means 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;
• participating in funding decisions; and
• determining the effectiveness of all efforts to promote the mental health and well being of children and youth.

For more information go to www.systemsofcare.samhsa.gov

The Ambassador’s Guide

A TOOL KIT developed to help:
• Disseminate the definition of family-driven care with fidelity;
• Apply its principles with integrity;
• Use its characteristics to help transform the way service is delivered; and
• Insure families are involved in making decisions.

Get the CD from the Federation of Families for Children’s Mental Health
www.ffcmh.org
Family or Parent Partner in the Context of Wraparound

- The Family Partner is a formal member of the wraparound team whose role is:
  - to serve the family
  - help the family engage and actively participate on the team
  - help the family make informed decisions throughout the process.
- Family Partners have a strong connection to the community and are very knowledgeable about resources, services, and supports for families.
- The Family Partner’s personal experience is critical to their earning the respect of families and establishing a trusting relationship that the family values.

For more information go to www.rtc.pdx.edu/nwi

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Keys for Networking

Accomplishments

- Studied the role of family support as a practice for 5 years.
- Described the scope and sequence of what it takes to provide parents with information, support, and training so that they can “drive care.”
- Engaged AIR, FFCMH, and a national group of experts to study:
  - What Keys for Networking has done and
  - Isolate practices and define attributes of parent support.

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Keys for Networking

10-Step Model

- Identifies 10 step continuum of parent readiness – from a simple initial inquiry to state level advocacy and supporting other parents.
- Identifies what information, training and support is appropriate for parents at each level.
- Tracks what has been provided to each parent and notes when they move to the next step on the continuum.

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A Perspective on Family Involvement
in New Jersey’s Children’s Behavioral Health System

Marlene Penn
Project Director
NJ Alliance of Family Support Organizations

We cannot assume that families can and will start tomorrow driving their own child’s care or state systems of care.

Are you interested in looking at the principles or the fidelity instrument?

For more information go to www.keys.org or send a message to Jane Adams: jadams@keys.org

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Levels of Family Involvement
NJ Division of Child Behavioral Health Services

• POLICY:
  – Members of Statewide system design workgroups and advisory boards
  – Write and review RFP’s
• MANAGEMENT:
  – Statewide Management Team
  – Quality Assurance and Performance Improvement Committee
  – Training and Technical Assistance
  – Board Members of local agencies
• SERVICES
  – FAMILY SUPPORT ORGANIZATIONS
  – Family creation of own team

Family Support Organizations (FSOs)

• Private Non-Profit organizations run by and for families who have children with behavioral, emotional, or mental health needs
• Staff and volunteers strive to ensure that the “Family Voice” is heard at every level of the system
• Funded through contracts with the NJ Division of Child Behavioral Health

The Local System of Care
New Jersey Department of Children and Families, Division of Child Behavioral Health Services

Family Support Organization Roles and Service Responsibilities

• Family Support Organization / Care Management Organization Strategic Partnership

Youth Partnerships New Jersey
Youth Advocacy Organizations formed and run by youth with emotional, behavioral or mental health needs. Membership is on a voluntary basis and youth must be between the ages of 13 – 21.

“I want other youth to know that I understand where they are coming from.”

Glenn Williams, Hudson County

Federation of Families for Children’s Mental Health
Efforts to Promote Family-Driven Care

Kim Williams
Co-Family Involvement Resource
Specialist for the Technical Assistance Partnership for Sandra Spencer
Underlying Assumptions

• A well-developed training curriculum broadly and effectively disseminated will positively impact the evolution of family drivenness in the children’s mental health field.
• Family-driven applies to the development and dissemination of this curriculum and can best be accomplished through the leadership of the national Federation and its constituency.
• The support and partnership of the national evaluation team, their consultants, and SAMHSA, CMHS, CAFB will add to the curriculum’s quality, effectiveness and credibility in the field.

Efforts to Promote Family-Driven Care

• Ambassador’s Guide Tool Kit CD is available from the Federation – 86 distributed to date.
• Orientation session at FFOMH Conference in 2006.
• Federation will lead effort to produce standardized curriculum (CAFB funded) incorporating components of the working definition of Family-driven Care.
  - Develop, pilot, and disseminate
    - 1 train-the-trainer presentation
    - 2 community based presentations
    - Web-based training, archived with interactive chat capacity
• The Federation will work with the national evaluation team to develop a process for measuring effectiveness of the curriculum.

What Do You Think?