

Family-Driven, Youth-Guided Care Family & Professional Partnering for Outcomes

family

\ 'fam-ile\ *n. pl, 1* : the fundamental

social group in society typically consisting of a

or two parents and their children 2 : two or more

people who share goals and values, have long-term

commitments to one another, and reside usually

in the same or place

or place of a shared business

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Parenting Can Be A Challenge

- The vast majority of families raising children with mental health needs are **healthy families** who are experiencing a particularly stressful challenge
- “Good parenting” **skills don’t usually work** when a child has mental health needs – when they hear voices, are extremely depressed or anxious, have compulsive behaviors, or harm themselves
- Disciplinary strategies that work with “typically-developing” children **are not effective** for “behavior problems” related to mental health

Family-based service concepts

- ▶ **Family-focused** – with the family as a target of therapeutic interventions – began in the late 1950s to early 1960s
- ▶ **Family-centered** care emerged in the late 1980s with increasing recognition of the role of families in a child's health and well-being
- ▶ Early models of wraparound promoted families as resources and partners; by mid-2000s, “**family voice and choice**” became a core principle
- ▶ In 2003, President's New Freedom Commission on Mental Health released six goals for a transformed MH system; goal #2 is, “Mental health care is consumer and **family driven.**”

Aren't they all the same?

| | Family-focused | Family-centered | Family-driven |
|-------------------|---|---|---|
| View of family | Potentially part of "the problem" | Potentially part of "the solution" | Vital to improved health of children |
| Role of family | Object of therapy | Key informant on the child & what works | Authority over the health care of their children |
| Decision making | Provider is primary decision maker | Family has input into decisions | Family makes informed choices |
| Outcomes - Family | Treatment adherence | Parent satisfaction | Parent empowerment & increased skills |
| Outcomes - System | Improved relationship between family and provider | Increased transparency and coordination | Families become important cog in system improvement |

Family-driven care defined

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 culturally and linguistically competent supports, services, and providers
- Setting goals
- Designing, implementing and evaluating programs
- Monitoring outcomes
- Partnering in funding decisions

How did we get here?

- ▶ Many families felt disenfranchised
 - Children's mental health problems poorly identified and diagnosed
 - Ineffective service plans
 - Parents blamed, frustrated, despairing
- ▶ Yet parents, against all odds, remained committed to their children
 - Parents fought, often heroically, for their children

Changing model of care

▶ Traditional Model

- Practitioner-based
- Problem-based
- Professional dominance
- Cure or cessation of symptoms
- Facility-based

▶ Family Driven Model

- Family-directed
- Child-centered
- Strengths-based
- Skill acquisition
- Quality of life
- Community-based

The Relational Stance

- ▶ From problem to competence
- ▶ From expert to Accountable Ally
- ▶ From professional turf to family turf
- ▶ From “*teaching to*” to “*learning with*”

[8]

An apt metaphor for this new paradigm of service delivery is the image of the family **in the driver's seat**... if one begins with the fact that the family's life is at issue, then they have the right to be in charge. If they have the best knowledge of their own needs, strengths, culture, and goals, then **their place is behind the wheel** – in control. The service provider belongs in the passenger seat. After working out the route with the driver, the provider can hold the map and act as a guide and support. If we believe that families know what they want and need, and that professionals are consultants hired by the families to help them reach their goals, then we are creating the blueprint for a family-designed system of services.

[3]

Important principles of FDC

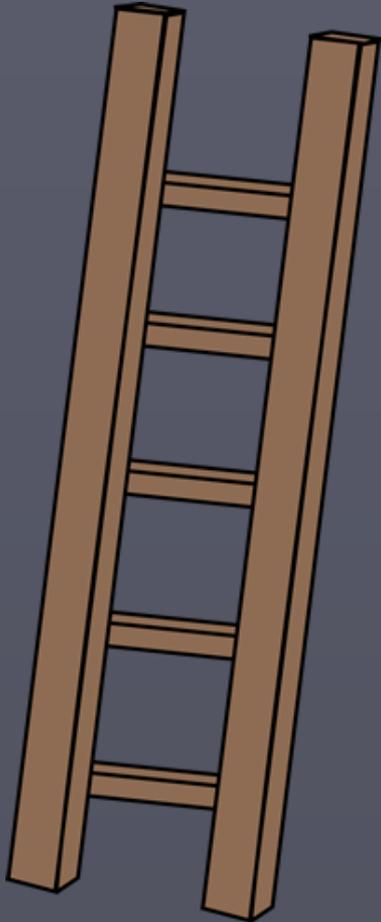
- “Family” is defined by families themselves
- Families are the experts on their children
- Families and providers work collaboratively as partners
- Decisions are made by families from an individualized set of choices
- Services are culturally appropriate/relevant
- A holistic approach is used
- The focus is strengths-based
- Parent peer support for families is available, encouraged and facilitated
- Family-run organizations help families develop a “collective voice”

Youth-guided care

Youth-guided means that young people have the right to be empowered, educated, and given a decision making role in the care of their own lives



Ladder of Youth Involvement



- ▶ Step 9: Youth-initiated & directed
- ▶ Step 8: Youth-initiated, shared decisions with adults
- ▶ Step 7: Youth & adult-initiated & directed
- ▶ Step 6: Adult-initiated, share decisions with youth
- ▶ Step 5: Consulted & informed
- ▶ Step 4: Assigned & informed
- ▶ Step 3: Tokenism
- ▶ Step 2: Decoration
- ▶ Step 1: Manipulated

“There are 2 phases of change in the system of care.

The first change is **in the system** itself.

The other change is **in ourselves** in harmonizing with the changes in the system.”

~ Robert Cavat

Role of Power

“Only by changing how we think can we change deeply embedded policies and practices. Only by changing how we interact can shared visions, shared understandings and new capacities for coordinated action can be established.”

[12]

Peter Senge, *The Fifth Discipline Handbook*

Role of Power

Ideal relationship occurs when families and professionals realize that the “power” resides in the system with both groups working together to enhance their effectiveness.

Why move toward FDC?

- ▶ Promotes values that resonate with families
 - It fulfills the promise of “nothing about us without us”
 - It supports a professional code of ethics
 - It enables professionals and providers to start “where the family/youth is,” as opposed to “where we want them to be”
- ▶ To get better results and to change systems

Families as change agents

“Parent involvement is not some kind of fad that will pass; it is the core of systems change. It is the only thing that can make reform in human services possible.”

Orrego, *Parents Leading the Way*

Family organizations as change facilitators

Families expand their *individual* role and impact

Family voice and choice leads the *team* process

Family organizations strengthen *collective* family voice

Wraparound & family-driven care

- ▶ Wraparound and family-driven care are highly compatible concepts
 - Highly similar principles and values
 - “Grew up” side-by-side
- ▶ Coordinated Services Team initiative is based on the wraparound model
- ▶ Many wraparound proponents view trained parent peer support as an “essential and non-negotiable” component
 - Most often delivered by family-run organizations, which also play a vital role in family-driven care

One county's experience: St. Croix

- ▶ Promotes family-driven care through parent representation on coordinating committee and contracting for parent peer specialist services
 - Currently 2 parents on coordinating committee; looking to increase parent members
 - Partnered with Wisconsin Family Ties for over 7 years by contracting for parent peer specialist

Parent Peer Specialists in Wraparound

- ▶ Acting as a mediator, facilitator, or bridge between families and agencies
- ▶ Ensuring wraparound fidelity
- ▶ Helping the team understand the parent perspective
- ▶ Preparing for and supporting Individualized Education Program (IEP) meetings
- ▶ Sharing personal experiences that can help teams to develop creative strength-based options
- ▶ Taking calls and providing support at times professionals are typically unreachable
- ▶ Helping families process their frustrations and concerns, thereby freeing up time for the Service Coordinator
- ▶ Saying things that need to be said that other team members may not feel comfortable saying

Exercise – Empowering Families



Benefits of family-driven care

- ▶ Allows for shared responsibility
- ▶ Builds families' skills, connections and confidence
- ▶ Brings creative and non traditional connections, resources and supports to the table
- ▶ Parent peer support helps to build a bridge of trust between parents and professionals
- ▶ Family and professional partnerships are key to breaking the stigma and moving beyond blame
- ▶ Provides more honest and accurate feedback on services that are being delivered

“The family is the cornerstone of our society. More than any other force it shapes the attitude, the hopes, the ambitions, and the values of the child. And when the family collapses it is the children that are usually damaged. When it happens on a massive scale the community itself is crippled. So, unless we work to strengthen the family, to create conditions under which most parents will stay together, all the rest - schools, playgrounds, public assistance, and private concern - will never be enough.”

~ Lyndon Baines Johnson

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