

## Need for a Definition of Family Driven Care

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In 2003, the President's New Freedom Commission on Mental Health issued "*Achieving the Promise: Transforming Mental Health Care in America.*" Goal 2 of that report calls for "consumer and family driven care." The report cites research showing that hope and self-determination play a key role in recovery. The Commissioners insisted that families "must stand at the *center* of the system of care." They also said that the needs of children, youth, and families must "drive the care and services that are provided."

"Consumers and families told the Commission that having hope and the opportunity to regain control of their lives was vital to their recovery."

The report did not say what family driven care should look like. But, it did make five

recommendations giving clues about what they meant.

1. Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.
2. Involve consumers and families fully in orienting the mental health system toward recovery.
3. Align relevant Federal programs to improve access and accountability for mental health services.
4. Create a Comprehensive State Mental Health Plan.
5. Protect and enhance the rights of people with mental illnesses.

### Why Promote Family-Driven Care?

Families, youth consumers, and family oriented practitioners echo the findings and recommendations of the 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.

Families and providers both need help to:

- view the decision making process differently;
- to act and interact in new ways;
- to feel comfortable with shared responsibility for decision making; and
- to own and believe in a family-driven approach as the right way of working together.

Providing family-driven care requires a major change in how people think and act. There must be administrative support to change behaviors and relationships. Developing, promoting, and supporting a commonly accepted definition of family-driven care is a necessary step in helping people change how they think and act.

### **Steps in the Process**

At its spring 2004 meeting, the Council for Collaboration and Coordination (the CCC)<sup>1</sup> asked the Federation of Families for Children’s Mental Health to help develop a clear definition of the term “family-driven”. The authors of this article took on this task. The process for developing the definition involved a sequence of activities, which always included asking for feedback. Feedback after each activity was incorporated into a new draft of the definition that was then used for the next activity.

The first steps were forming an expert panel and interviewing recognized leaders in the family movement. These two activities provided information that was used to develop the first draft definition. This draft was used to stimulate feedback in open forum discussions at a national meeting in June 2004. More input, gathered during the summer and fall of 2004, from staff of the Child, Adolescent and Family Branch and a variety of audiences around the country resulted in a series of eight drafts. Then, the Family Work Group of the CCC held a conference call to discuss the definition and provided a number of specific suggestions. After these suggestions were incorporated, the draft was sent out to the original expert panel members. Their feedback and comments led to further refinements. By February of 2005, a Working Definition of Family-driven Care along with principles and characteristics were developed. It was the 10<sup>th</sup> version. This version was translated into Spanish as well.

From February to October 2005, the definition was circulated widely and more feedback was collected. There was a Webinar (seminar on the internet), and the draft definition was posted on several internet sites. A PowerPoint presentation was made available. The authors presented the draft definition at dozens of conferences. A wide variety of people discussed the definition in seminars and workshops throughout the country. Reaction was very positive during this time. There was wide acceptance for the definition among leaders in all the systems that serve children

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<sup>1</sup> What is the Council for Collaboration and Coordination (the CCC)? The federally funded Comprehensive Community Mental Health Services Program for Children and Their Families – often called the systems of care program – has funded over 100 community based systems of care. This program is supported by a number of centers. Some provide technical assistance, others evaluation, research, and training. The Council for Collaboration and Coordination is made of leaders from all these groups plus representatives of funded communities. They meet regularly with, representatives from the government staff from the Child, Adolescent and Family Branch of the Center for Mental Health Services.

with mental health needs including professionals from education, child welfare, mental health, juvenile justice, and health. Families liked the definition very much, but asked us to add something about how the definition applies to funding services. A few additions were made in November 2005, and the 11<sup>th</sup> version was released at the Federation's 17<sup>th</sup> Annual Conference.

## **Working Definition of Family-Driven Care – revised November 2005**

### **The Definition**

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

### **Guiding Principles of Family-Driven Care**

1. 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.
2. Families and youth, providers and administrators embrace the concept of sharing decision-making and responsibility for outcomes.
3. Families and youth are organized to collectively use their knowledge and skills as a force for systems transformation.
4. Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
5. Families and family-run organizations provide direction for decisions that impact funding for services, treatments, and supports.
6. Providers take the initiative to change practice from provider-driven to family-driven.
7. 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.
8. Community attitude change efforts focus on removing barriers and discrimination created by stigma.
9. Communities embrace, value, and celebrate the diverse cultures of their children, youth, and families.
10. Everyone who connects with children, youth, and families continually advances their own cultural and linguistic responsiveness as the population served changes.

### **Characteristics of Family-Driven Care**

1. Family and youth experiences, their visions and goals, their perceptions of strengths and needs, and their guidance about what will make them comfortable steer decision making about all aspects of service and system design, operation, and evaluation.

2. Family-run organizations receive resources and funds to support and sustain the infrastructure that is essential to insure an independent family voice in their communities, states, tribes, territories, and the nation.
3. Meetings and service provision happen in culturally and linguistically competent environments where family and youth voices are heard and valued, everyone is respected and trusted, and it is safe for everyone to speak honestly.
4. Administrators and staff actively demonstrate their partnerships with all families and youth by sharing power, resources, authority, responsibility, and control with them.
5. Families and youth have access to useful, usable, and understandable information and data, as well as sound professional expertise so they have good information to make decisions.
6. Funding mechanisms allow families and youth to have choices.
7. All children, youth, and families have a biological, adoptive, foster, or surrogate family voice advocating on their behalf.

### **Putting Families Behind the Wheel**

The term “family-driven care” can be thought of as a road trip. Picture a comfortable car or minivan filled with good traveling companions. The main passenger is a child who has a mental health need. The driver is the child’s family. The rest of the passengers have been invited along because they know a lot about child development, education, health, family support, psychology, literacy, housing, employment, and other things families need to have a good quality of life. The family knows where they want to go but need help choosing a good route and getting there safely. The traveling companions share what they know and discuss all the options together with the driver. Then the family takes the wheel drives the car along the chosen route. The driver gets help along way if it is needed. At the end of the trip, everyone celebrates their success together.

This image of a journey was presented to the New Freedom Commission by the Federation of Families for Children’s Mental Health. The image has been used to help families and professionals understand how to apply the definition of family-driven care in their everyday lives in the real world. Some practical strategies for taking the wheel have been developed to get folks started on their own journey. TIPS for SUCCESS are included in this newsletter.

### **Web References on Family-Driven Care**

- ✓ Working Definition and tools: [www.ffcmh.org/systems\\_what\\_is.htm](http://www.ffcmh.org/systems_what_is.htm)
- ✓ Webinar and supporting documents – follow links under Defining Family Driven Care to: View the PowerPoint slides for the Webinar; View the definition of family-driven care; Read the story "Journey to Family-Driven Policy;" or post a message to the discussion board: [www.tapartnership.org/advisors/family/the\\_family\\_page.asp](http://www.tapartnership.org/advisors/family/the_family_page.asp)
- ✓ Achieving the Promise: Report of the President’s Commission on Mental Health: [www.mentalhealthcommission.gov/reports/FinalReport/toc.html](http://www.mentalhealthcommission.gov/reports/FinalReport/toc.html)
- ✓ [www.systemsofcare.samhsa.gov](http://www.systemsofcare.samhsa.gov)

**SYSTEM PARTNERS HAVE A RESPONSIBILITY TO INSURE THAT FAMILIES HAVE PRACTICAL OPPORTUNITIES GET THE TRAINING THEY NEED TO DRIVE SAFELY !!**

**TIPS For SUCCESS**

**Ways to Take the Wheel --- at the start**

- ‡ Ask/explain about the steps ahead and what to expect along the way.
- ‡ Ask/tell about including other agencies involved with your child and family and getting relevant information from them (such as an Individualized Education Program (IEP)).
- ‡ Ask for/offer referrals for services to meet your child's needs.
- ‡ Ask for/give explanations of all options and ask for the support your family would need to make things work for your child.
- ‡ Request/offer services that teach your child how to adapt successfully in their schools and communities.

**Ways to Take the Wheel --- as things move along**

- ‡ Find out/tell about all opportunities to participate in planning and advocate for your child's and your family's services and supports.
- ‡ Talk/connect with professionals to learn the evidence about the kinds of treatments, services, and supports that can help achieve your goals.
- ‡ Seek/offer opportunities to develop new skills to build (or rebuild) and sustain good relationships with your child.
- ‡ Insist on making/provide discharge, and aftercare plans for reintegration into the community at the outset of out-of-home care.
- ‡ Ask/offer for help to find the right services and providers and funding to pay for them.

**Ways to Take the Wheel --- sustaining gains**

- ‡ Request/provide services that support your child's gains and will help insure they continue to adapt successfully in their schools and communities.
- ‡ Ask/offer for supports that can help your family cope with the stress at home – including support for siblings.
- ‡ Seek/offer services that promote wellness and resilience.
- ‡ Insist on/provide services that build on your child's and family's strengths and counterbalance risk factors.

**Ways to Take the Wheel --- at a Judicial Proceeding**

- ‡ Find/provide a family advocate attached to the court or other knowledgeable and trustworthy person who can help you learn what you need to know and prepare for court.
- ‡ Ask/provide for a description of the courtroom and the court proceedings before hand – including any security measures you are likely to encounter.
- ‡ Get/offer help to prepare any statements you wish to make during the proceeding.
- ‡ Request/provide transportation, child care, and qualified, professional translators (if necessary) so you can fully participate in the hearing.