



The Federation of Families  
for Children's Mental Health  
Colorado Chapter

# BUILDING A FAMILY-RUN ORGANIZATION: PART II

## AFFILIATE DEVELOPMENT

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**September 18, 2013**



OMNI Institute  
899 Logan Street  
Denver, CO 80203

# INTRODUCTIONS

- **The Federation of Families for Children's Mental Health~Colorado Chapter**  
(CO Federation)
- **Family Agency Collaboration (FAC)**

**Sponsored by the \*SAMHSA Statewide Family Network Grant**  
(\*U.S. Substance Abuse and Mental Health Services Administration)

# GOALS FOR TODAY

- Learn why **Families Start Family-Run Organizations**
- Recognize the **unique role and value of Family-Run Organizations** in changing child and family services.
- Understand **initial steps for starting a Family-Run Organization** (e.g., structure, focus, membership, board development)
- Consider partnership **opportunities and advantages** working with the CO Federation of Families for Children's Mental Health

# AGENDA

- **What is a Family-Run Organization?**
- **Goals of a Family-Run Organization**
- **Building your Family-Run Organization**
  - **Structure**
  - **Focus**
  - **Membership**
  - **Board Development**
- **Available Resources**
- **Next Steps**

# WHAT IS A FAMILY-RUN ORGANIZATION

## **Colorado Definition:**

*An organization with the explicit purpose to serve families who have a child, youth, or adolescent with special physical, mental, emotional, behavioral, substance use, developmental and/or educational needs.*

**It is governed by a board of directors and comprised of a majority of individuals who are family members.**

# SAMHSA'S FAMILY-RUN ORGANIZATION DEFINITION

A family-run organization for children's mental health is one whose purpose is to serve families that have children and youth with serious behavioral, emotional, and mental health challenges.

**It is an organization governed by family members of children and adolescents with mental health challenges.**

Have parents and/or primary caregivers of children and youth with serious emotional, behavioral, or mental health needs as a significant percentage of its leadership and governance.

"Guide to Sound Business Practices for Family-Run Organizations in Children's Mental Health," Marche, 2012; p. 2

# CO FAMILY MEMBER DEFINITION

## **A Family Member:**

- Is a person who is raising or has raised a child, youth, or adolescent with special physical, mental, emotional, behavioral, substance use, developmental, and/or educational needs
- Has experienced working with many of the agencies and providers in their community
- Can be recognized and utilized as a collaborator by serving on state and local boards, committees and coalitions. A family member also can be hired as an Individual Service Plan care manager and/or facilitator, a family advocate, evaluator and trainer 7

# FAMILY MEMBER INVOLVEMENT

- Their own experiences
- Their own expertise
- Their own values and beliefs
- Their own attitudes
- Their own concerns and needs
- Their own strengths and resources



# FAMILY-RUN ORGANIZATION MEMBER INVOLVEMENT

**Family Run Organization members bring to the table:**

- The Collective Family Experiences
  - The Collective Family Expertise
  - The Values and beliefs
  - The Attitudes
  - The Concerns and needs
  - The Strengths and resources
- of the families they represent.

# WHAT SHOULD A FAMILY-RUN ORGANIZATION/AFFILIATE LOOK LIKE?

- Have an independent governing structure, separate from any child-serving agency.
- Give preference to family members as leaders and voices
- Promote family involvement at all levels:  
**Individual; Local; State and National**
- Provide opportunities for the “family voice” to be instrumental in shaping policies that meet the individualized needs of families and their children.
- Follow a “System of Care” Model

# FAMILY-RUN ORGANIZATIONS AND SYSTEMS OF CARE (SOC)

**Building the family movement on SOC core values:**

A system of care model is:

- 1) Child-centered and family focused**, with the needs of the child and family dictating the types and mix of services provided.
- 2) Community based**, with the focus of services as well as management and decision making responsibility resting at the community level

# FAMILY-RUN ORGANIZATIONS AND SOC (CONTINUED)

- 3) **Culturally and linguistically competent**, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve (Stroul et al., 2008)

From the: "Guide to Sound Business Practices for Family-Run Organizations in Children's Mental Health", March 2012 p. 6

# FAMILY-RUN ORGANIZATION GOALS

- 1) Teach, coach, and support families to navigate child-serving systems.
- 2) Teach, coach, and support the leadership of child-serving systems to work with and support families.
- 3) Provide information of rights of children, youth, parents and caregivers in all child-serving systems.
- 4) Promote family-driven and youth guided policies in their communities.

From the: Guide to Sound Business Practices for Family-Run Organizations in Children's Mental Health", March 2012 p. 2

# WHY START A FAMILY-RUN ORGANIZATION?

- To enhance opportunity for the unified voices of families to be heard in our State and in your community.
- To foster collaboration between families and local and State child-serving agencies.
- To recognize and capitalize on the gifts and talents of family members and provide appropriate tools and training for families to effectively carry out their valuable work.

# BECOMING AN AFFILIATE



# DETERMINING YOUR AFFILIATE FOCUS

- 1) Deciding on a population focus
- 2) Addressing broader community needs
- 3) Examples



# DETERMINING YOUR AFFILIATE STRUCTURE

- Why having a structure is important
- Formal/Informal?
- Large/Small?
- Composition of leadership, staff and volunteers?

# DETERMINING YOUR AFFILIATE BOARD MEMBERSHIP

- 51% or more Family members!
  - The expectation has been that family members of children and youth with serious behavioral, emotional, or mental health challenges make up 51% or more of the affiliate board.
  - Each board determines whether this is practical for their affiliate.
  - In order to limit board size, other strategies may be used, such as
    - Weighing votes, in order to ensure that the organization is family-run even if its board does not consist of the 51% family members.
- Representatives from state and/or local child-serving systems
- Service providers
- Community representatives

# DEVELOPING YOUR AFFILIATE BOARD

## Orienting your new board members

- Board Orientation Process
- Orientation packet
- Policy statements and procedures
- Orientation meeting

# THE CO FEDERATION EXPERIENCE

## OUR STORY

**1993: The CO Federation was started by CO families**, in partnership with the National Federation of Families for Children's Mental Health, the Mental Health Association of Colorado (now know as Mental Health America of Colorado) and the CO Department of Mental Health's (now known as the Office of Behavioral Health) Child and Adolescent Service System Program.

### **On-going commitment to:**

- Promote SOC values, principles and reform
- Influence the CO mental health and other child-serving systems to promote family-driven and youth guided polices in Colorado.
- Develop a network of family advocates
- Link with the national family movement and the National Federation
- Provide information and referral services to CO families.
- Create and sustain affiliate family organizations throughout Colorado

# THE CO FEDERATION EXPERIENCE

## Our Successes...

- Presence at National, State and Local Tables
- Provide support for families
- Offer technical assistance
- Incorporate unique contributions of CO families in our work
- The juvenile justice **Family Advocacy Toolkit** <http://toolkit.coloradofederation.org/>

# THE CO FEDERATION EXPERIENCE

## Our Success Continued.....

- **CO Family Advocate Training**
- **Co-writing of Legislative Policy**
  - House Bill Number 07-1057
  - House Bill Number 11-1193
  - Definition of Family Advocate
  - Definition of Family System Navigator

<http://collaboration.omni.org/sites/COFED/SitePages/Family-Org.aspx>

# THE CO FEDERATION EXPERIENCE

## **Our Challenges/Lessons Learned...**

- Balancing individual services for families with participation in systems change work (micro v. macro work)
- Pressure to represent family voice in broad range of contexts and groups with limited resources (establishing priorities)

# THE CO FEDERATION EXPERIENCE

- Cultural and Linguistic services: We should provide the effective foundations in order to successfully implement Culturally Responsive and/or Culturally Congruent Services that address ethnic, racial, linguistic, geographical, socio-economic, religious, spiritual, biological, as well as gender needs and variances.
- We can't do it alone; need to collaborate with other family organization partners



# THE CO FEDERATION EXPERIENCE

*Together, we will have the capacity  
to be the voice at every table!*



# COLORADO FEDERATION TOOLKIT

- **Where?**
  - Online
  - <http://collaboration.omni.org/sites/COFED/Pages/Home.aspx>
- **For Whom?**
  - Accessible to public
- **What does it contain?**
  - Resources for building family organizations
- **In what form?**
  - Literature, guides, sample documents

# COLORADO FEDERATION TOOLKIT

## Key Toolkit Resource Areas:

### **Understanding Families – Special Populations**

- Cultural Responsiveness
- Health Care Education and Enrollment
- Military Families
- Trauma and Trauma-Informed Care

### **Building a Family-Run Organization**

- *(Affiliate)* Board Development
- Evidence Based Practice Resources
- Family Involvement
- Funding and Sustainability
- Information Sharing
- Webinars and Presentations

# AFFILIATE BOARD RESOURCES AND TOOLS

- Sound Business Practices Toolkit
- Board Orientation Packet Template

<http://collaboration.omni.org/sites/COFED/SitePages/Family-Org.aspx>

# CO FEDERATION AFFILIATE TECHNICAL ASSISTANCE

- Monthly Conference Calls
- Subject-specific webinars
- Affiliate Development Mentoring/Coaching
- CO Federation Toolkit and Portal
  
- Trainings:
  - Family Advocate Training (based on Parent Support Program from Tennessee Voices)
  - Parent Professional Partnership
  - The Tale of O video and curriculum

# DISCUSSION

## Questions?

- 1) What are some ways you can move forward with building an affiliate organization in your community?
- 2) What resources and supports do you need?/What training and technical assistance (TA) would be most helpful?

# YOUR NEXT STEPS

- ✓ **Commit** to growing family involvement by building a family-run organization in your community!
- ✓ **Participate** in upcoming training offerings.
- ✓ **Explore** the toolkit
- ✓ **Share** your other TA needs with us.
- ✓ **Give us feedback** on the toolkit
- ✓ **Complete the on-line survey for today's webinar!**

# FUTURE WEBINARS AND WORKSHOPS

Fall  
2013

Becoming a CO Federation Affiliate  
CO Federation Affiliate Agreement  
Recruiting Board Members  
Strategic Planning

Winter:  
2014

Starting Support Groups  
Sustainability and Growth  
Organizational Self-Assessment

Spring  
2014

Youth Involvement



# PRESENTER CONTACT INFORMATION

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# RESOURCES

## **Federation of Families for Children's Mental Health~CO Chapter**

7475 W. 5<sup>th</sup> Avenue, Suite 307

Lakewood CO 80226

720 855-3493; Toll Free: 1.877.792.8886

[www.coloradofederation.org](http://www.coloradofederation.org)

## **National Federation of Families for Children's Mental Health**

<http://www.ffcmh.org/>

**SAMHSA** (Substance Abuse & Mental Health Services Administration; 1 Choke Cherry Road; Rockville MD 20857;

1 877-SAMHSA-7 (1-877-726-4727) [www.samhsa.gov](http://www.samhsa.gov)

# DEFINITIONS

- Child-Serving Systems/Agencies: Examples include but are not limited to mental health, substance abuse, primary care, education, child welfare, and juvenile justice systems.
- Community Representatives: Examples include but are not limited to: Non-traditional agencies and organizations, Clergy, Insurance Company Representatives, Legal, Juvenile Justice, Community Action Agencies, Recreational, policy-makers, law enforcement,

# DEFINITIONS

- Family-Driven: *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; and
    - Determining the effectiveness of all efforts to promote the mental health of children and youth
- <http://www.samhsa.gov/children/core-values.asp>

# DEFINITIONS

- Family Advocate (FA): A parent or caregiver who has raised or cared for children, youth or adolescent with mental health or co-occurring disorders and have worked with multiple agencies and providers in mental health, physical health, substance use, juvenile justice, developmental disabilities and other state, local service systems. A FA assists in accessing and receiving service for children, youth or adolescent with mental health or co-occurring disorders; The FA is a parent or caregiver trained in system of care approach to assist families in accessing and receiving services and supports for children and adolescents with mental health or co-occurring disorders.

# DEFINITIONS

- Family Systems Navigator: An individual who has been trained in a system of care approach to assist families, children and adolescents with mental health or co-occurring disorders in accessing and receiving services and supports and has worked with multiple agencies and providers, including mental health, substance use, juvenile justice, physical health, developmental disabilities, educational, and other state and local service systems.

# DEFINITIONS

- Linguistic competence: The capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills, or are not literate, and individuals with disabilities (Bronheim, Goode, & Jones, 2006).  
From the: "Guide to Sound Business Practices for Family-Run Organizations in Children's Mental Health", March 2012 p. 13
- SAMHSA: U.S. Substance Abuse and Mental Health Services Administration
- Service Providers: Examples include but are not limited to: mental health, substance abuse, recreational, vocational, health services, the educational and juvenile justice systems.

# DEFINITIONS

- Systems of Care: A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges of youth with serious mental health needs and their families. Families and youth work in partnership with public and private organizations to design mental health services and supports that are effective, that build on the strengths of individuals, and that address each person's cultural and linguistic needs. A system of care helps children, youth and families function better at home, in school, in the community and throughout life (Stoul et al., 2008 p.4)

From the: "Guide to Sound Business Practices for Family-Run Organizations in Children's Mental Health", March 2012 p. 5-6.



# SOC DEFINITIONS (CONTINUED)

- Child-centered: Services meet the individual needs of the child, consider the child's family and community contexts, and are developmentally appropriate, strength-based, and child-specific.
- Family-focused: Services recognize that the family is the primary support system for the child and participates as a full partner in all stages of the decision-making and treatment-planning process.
- Community-based: Whenever possible, services are delivered in the child's home community, drawing on formal and informal resources to promote the child's successful participation in the community.

# SOC DEFINITIONS (CONTINUED)

- Multisystem: Services are planned in collaboration with all the child-serving systems involved in a child's life.
- Culturally competent: Services recognize and respect the behavior, ideas, attitudes, values, beliefs, customs, language, rituals, ceremonies, and practices characteristic of the child's and family ethnic group.
- Least restrictive/least intrusive: Services take place in settings that are the most appropriate and natural for the child and family and are the least restrictive and intrusive available to meet the needs of the child and family.

From the: "Guide to Sound Business Practices for Family-Run Organizations in Children's Mental Health", March 2012 p. 3

# DEFINITIONS

- Youth-Guided Care: Youth-Guided means that youth are engaged as equal partners in creating systems change in policies and procedures at the individual, community, State and national levels.
- Youth-Guided Policy:
  - Youth are invited to meetings
  - Training and support is provided for youth on what the meeting is about
  - Youth and board are beginning to understand the role of youth at the policy-making level.

# DEFINITIONS

## **Youth-Guided Policy (Continued)**

- Youth can speak on their experiences and talk about what is really going on with young people.
- Adults value what youth have to say in an advisory capacity.
- Youth have a role in decision making.
- Youth have an appointed mentor who is a regular attendee of the meetings and makes sure that the youth feels comfortable to express his or herself and clearly understands the process.

**<http://www.samhsa.gov/children/core-values.asp>**

THANK YOU!

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