Institute #28
Models of Family-Run Organizations: One Size Does Not Fit All

Georgetown Training Institutes
July 2014

About FREDLA

- Family Run Executive Director Leadership Association
- Started in 2012 by 15 Executive Directors of family-run organizations
- Mission: To develop leadership and organizational capacity of family-run organizations dedicated to children’s behavioral health

Presenters

- Tom Dillingham - Federation of Families - Colorado Chapter
- Lisa Lambert – Parent/Professional Advocacy League, Massachusetts
- Candy Kennedy-Goergen – Nebraska Federation of Families
- Jane Plapinger – Maryland Coalition of Families
- Jane Walker – Family Run Executive Director Leadership Association

Agenda For Today

1. History of family movement and evolution of family organizations
2. Four states – four models
3. What does your state model look like?
4. Common elements
5. Hybrid and emerging models

Family-Run Organizations

- Dedicated to supporting families caring for a child or youth with mental, emotional, behavioral or substance abuse needs
- Governance - Board is comprised of at least 50% family members
- Personnel - Executive Director and all staff members providing support are family members with “lived experience”
- Promote family voice at all levels of the organization and system

History of Family Movement

- Began in 1980's – Federal funding for states to receive Child and Adolescent Service System (CASSP) grants required “family input into the planning and development of service systems, treatment options and individual service options.” Only 9 family organizations at the time.
- 1985 - Federal support for Statewide Family Networks (SFNs) - $20,000
- 1988 – National Federation of Families started
- 2000's – Number of funded SFNs grew to 45 - $60,000
- Currently – 29 SFNs
What Family Organizations Do

- Information and communication network
- Act as a voice for families
- Provide training for families and professionals
- Develop products and information campaigns
- Collect and compile family/sibling support
- Advocate
- Foster relationships with multiple stakeholders
- Public education
- Support and evaluation of state funding
- Data collection and evaluation
- Cultural fluency and language interpretation

Powerful Purpose

- Enhances opportunities for voices of families to be heard
- Fosters collaboration between systems and families
- Recognizes and capitalizes on the gifts and talents of family members and provides appropriate tools and training for families to carry out effective work
- Creates unique and empowering support systems for families
- Establishes a unified voice for families

2014 Survey of Statewide Family Networks

- Statewide Family Networks have been around for a long time:
  - More than 20 years 10
  - 11-20 years 16
  - 6-10 years 1
  - 5 years or less 5

2014 Survey

- In the last fiscal year, Statewide Family Networks supported or trained over 109,000 families and professionals.
- Total budgets for the 31 Statewide Family Networks are approximately 27.3 million dollars.
- 8 SFNs have budgets from 4.4 million dollars
- 19 SFNs have budgets ranging from $100,000 - $999,999 with an average budget of $136,420.
- 6 SFNs have budgets less than $100,000 and rely solely on SFN grants for funding.
- Statewide Family Networks employed 443 family members in the 31 organizations

2014 Services

- 50% of SFNs provide training for families
- 63% provide information and referral
- 50% provided one-to-one support to families

Reasons Families Contact Statewide Family Networks

School-related issues are the most frequent reason families contact a SFN.
Stages of Non-Profit Development

- Grass Roots - Invention
- Start-Up - Incubation
- Adolescent – Growing
- Mature - Sustainability
- Stagnation & Renewal
- Decline And Shut-Down

Components of Non-Profit Organizational Development

- Program & Services
- Leadership & Management
- Staffing
- Governance
- Administration
- Finances/Fundraising
- Marketing/Awareness

Non-Profit Life Cycle Matrix

Components of a non-profit develop at different rates and therefore are often at different stages of development.

How Does all of This Impact the Structure of a Family Organization?

- History/geography in your state/region/community
- Stage of organizational development
- External environment – grants, legislation, law suits
- Internal decisions – strategic plans/decisions
- Transitions – funding, leadership

Models of Family-Run Organizations

- Affiliate Model
- Umbrella Model
- Centralized Model
- Advocacy Model

Similar But Unique
Colorado Federation of Families

Tom Dillingham, Executive Director

OUR STORY
- 1993: The CO Federation was started by CO families, in partnership with the Federation of Families for Children’s Mental Health, the Mental Health Association of Colorado and the CO Department of Mental Health’s Child and Adolescent Service System Program.
- Ongoing commitment to:
  - Promoting System of Care values, principles and reform
  - Influencing the CO Mental Health and other child-serving systems to promote family-driven and youth-guided policies in Colorado.
  - Develop a network of family advocates
  - Create and sustain affiliate family organizations throughout Colorado
  - Provide information and referral services to CO families.
  - Continue to link with the national family movement (FREDLA - The National Federation, etc.)

Colorado Federation Structure
- Colorado central office – administrative hub – 9 employees
- Central office role is to develop local affiliates
- 3 Affiliates – flexible - set up how they look – may have formal Board – some have employees some may not have employees but rather volunteers
- 12 Potential affiliates through System of Care Expansion Grant
- Application process – agree to have formal Board
- One affiliate Board member from each affiliate sits on central Board

The Colorado Federation Experience

Our Successes...
- Presence at State and Local Tables
- Providing support for families
- Offering technical assistance
- Incorporating unique contributions of families in our work

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)
- Can’t do it alone; need to collaborate with other family organization partners

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

Nebraska Federation of Families for Children’s Mental Health

Candy Kennedy-Goergen, Executive Director
Maryland
Maryland Coalition of Families for Children's Mental Health
Jane Plapinger, Executive Director

Structure - History
- For 12 years pockets of family organizations in two regions of the state with no statewide or unified voice for families
- Started in 1999 - Initially a coalition of five independent family groups based on state's offer to fund “one statewide organization”
- At five-year strategic planning process the MCF Board made strategic decision to become provider rather than coalition and developed centralized structure with regional offices

Structural Features
- One incorporated 501(c)(3) organization
- Centralized administration and fiscal management
- Centralized statewide program functions:
  - Public education
  - Advocacy
  - Policy
  - Training
- Regional offices (7) with family support direct service staff

Fiscal Structure
- Revenue sources
  - State general fund infrastructure grant
  - Grants from local management boards in some counties for information, referral and navigation
  - Research grants (sub-vendor providing family support staff)
  - Federal grants (SAMHSA) and state IDEA grant
  - Billing Medicaid and care management entity for peer family support services

Strengths and Challenges of Model
- Centralized fiscal and administrative management is efficient and manages risk
- Dispersed regional staff is challenging to supervise
- Regional staff work in their communities and develop strong local partnerships
- Local funding support varies from region to region – uneven coverage within state
Role of Funding

- Has determined where we provide services
- Most grants are competitively procured; hard to do long-term planning
- Billing rates from Medicaid and Care Management Entity inadequate; need supplemental grant funding
- Inadequate infrastructure funding; most funders want to pay direct program costs only

Massachusetts

Parent Professional Advocacy League
Lisa Lambert, Executive Director

Beginnings

- State response to parent calls
- Single source of funding
- Director’s focus: unify support, direct advocacy efforts
- Overstepping and new director
- Battle to remain single organization in state
- New focus: unify family support leaders; seek additional funding sources

Cart Before the Horse

- All staff advocate; all staff support families
- Need for coordination and unrestricted funding
- Policy and advocacy work create partnerships and tensions
- Moving from individual to systems advocacy; from insider advocacy to outsider advocacy
- Polarities: Oversight vs. coordination; creating a network vs. organization; trust vs. pushing the boundaries
- Building a board that can invest in advocacy

Key Junctures

- Funding created structure: state funds through provider agencies
- Federal lawsuit: Rosie D v. Romney
- Using SAMHSA funding to create network
- Choosing not to become a Medicaid provider
- Seizing opportunities
  - Becoming a training expert
  - Providing technical support

Infrastructure mirrors priorities

- PPAL board
- Research
- Outreach to diverse families/health/MVC/Integrated Care
- Training and technical assistance
- PolicyStakeholders
- Family partners
- Provider agencies
- Federal partners
- Trust vs. pushing boundaries
- Professional and families
- Technical assistance
Challenges

- Good—bad dynamic ebbs and flows
- Capacity struggles to match demand
- When all staff is doing advocacy/training/support, little is left for capacity building or administrative tasks
- Constantly seeking new funding
- More outflow of resources; little influx
- Need for champions and partners

Funding—Lessons Learned

- Early lesson—never chase funding that is not a match
- Be creative—use board and "friends" to brainstorm
- Lessons learned from Rosie D
- Diversify, diversify
- Invest in relationships with funders; promote their organization
- Reframe: Ensuring family perspective through research is a form of advocacy
- Not "owned" by any one funder

Achievements

- Learning new approaches: social media, traditional media, listening sessions
- Acquiring power and credibility—balancing the scales
- Many bills passed into law
- Families want to give back
- Using insider/outsider skills to ensure partnerships

Final Thoughts

- Structure must support activities
- Funding must support work and not define it
- A strong board can provide bridge to relationships, funding and strategic steps
- Remember your "constituency" are families

Exercise

What does your organization’s structure look like?

Instructions

- Using the markers, draw a picture of your organization’s structure/functions
  - Use
    - Blue = governance
    - Green = administration
    - Red = services
    - Black = other
Group Exercise

- With the people at your table, describe the structure of your organization to others at the table – 2-3 minutes each.
- Together discuss how your family-run organization manages one of the organizational functions that is assigned to your table.
  - Advocacy
  - Administration
  - Grant-writing/fundraising
  - Marketing/awareness
- Together compare and contract how different structures handle these functions.
- Are there advantages/disadvantages to one structure?

Common Threads

- Mission
- Advocacy
- Leadership
- Adaptability

Let's Talk About Your Mission

- What's included in a mission statement?
  - What you do
  - Who you do it for
  - Why you do it
- Why do you need one?
  - Clarity for donors, partners, volunteers
  - To open your doors for families
  - To measure what you are doing against what you say you should be doing

Being Mission Driven

- Nonprofits are guided by their mission
- Each staff member and board should be able to be an ambassador and articulate mission
- Vision (perfect world) vs action plan (organization's work)
- Creates a message to others about your intention
- Must be updated periodically

What is Mission Drift?

- When an organization moves away from its original direction by accident
  - May be chasing the money
  - Staff or board may see natural extension into related areas
  - Desire to serve different population
- When an organization changes direction on purpose
  - Okay if discussed and ratified by board
  - All considerations happen per bylaws, inform IRS, state and other stakeholders

Mission Strength, Drift Impact

- Adherence to mission
  - Gain unique niche, energize and inspire others
  - Increase credibility
  - Attracting resources and funding
  - Connections and partnerships
- Straying from mission
  - Creates confusion internally and externally
  - Loss of credibility (funders, volunteers, partners)
  - Loss of focus
  - You begin to serve others – not families
Can’t Brand Without It

- What makes your organization unique?
- How do you sell or market your work?
- Instant recognition
- Marketing in the age of social media
- Creating a safe but exciting network

Advocacy

- For a family – e.g. at an IEP meeting
- Within the system – serving on committees, using legislative process
- Outside the system – partnering with other organizations, using media
- Important to have a unified family voice at the table
- Characterized by respect, integrity and trustworthiness

Leadership

- Come into this work because of child – not necessarily training or experience
- Challenges of transitioning from founder
- Executive director – broad skill set required given limited infrastructure
- Culture and composition of majority-family boards; expectations?
- Ability to develop and maintain relationships with diverse partners

Adaptability

- In changing times, organizations fare better if they adjust their practices, structures or procedures to cope with a changing environment, such as a shifting economic landscape, new legislation impacting their field or the introduction of a new organization or technology.
- Case examples of not adapting to changes in environment:
  - Erols – video rental
  - Borders Books – bookstores
  - Gateway – computers
  - Circuit City – electronics
- Case examples of adapting to changes and re-defining image:
  - March of Dimes – polio
  - Mental Health America
  - United Way of America – corruption
  - ARC

Hybrids and Emerging Structures

- Hybrid: A thing made by combining two different elements
- Mergers: Consolidation by one company taking over another company
- Increasing role of technology in human services

We welcome your questions or comments!
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