

Nothing About Families without Families: Effective Strategies for Diverse Family Leadership and Engagement

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Family Engagement & Leadership: Why & How?

The evidence supporting the value of family engagement, and evidence-based strategies to make it happen!

Presenters:



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Types of Exemplary Leadership

Consider the following types of leadership. Where does your leadership fit? Identify at least 2 types of leadership that you demonstrate and give one example for each.

- **(1) Challenging the process**

- In challenging the process, a leader identifies what isn't working and raises concerns about the process and outcomes.

- **(2) Inspiring a shared vision**

- In inspiring a shared vision, a leader motivates and supports others to come to consensus about what is and isn't working in a particular situation or system and what the end goal(s) is/are.



- **(3) Enabling others to act**

- In enabling others to act, a leader provides the supports and encouragement to others to act on behalf of the shared vision to change the process and outcomes.

- **(4) Modeling the Way**

- In modeling the way, a leader leads by example, demonstrating effective leadership by their actions.

- **(5) Encouraging the heart**

- In encouraging the heart, a leader provides emotional support to others to support their leadership and keep them strong and committed even in the face of disappointment.

What do they mean to you?

- Brainstorm what each of these words means:
 - “Involvement”
 - “Advocacy”
 - “Leadership”
 - “Empowerment”
- Are there differences/similarities based on your perspective?

The Basis of our Work

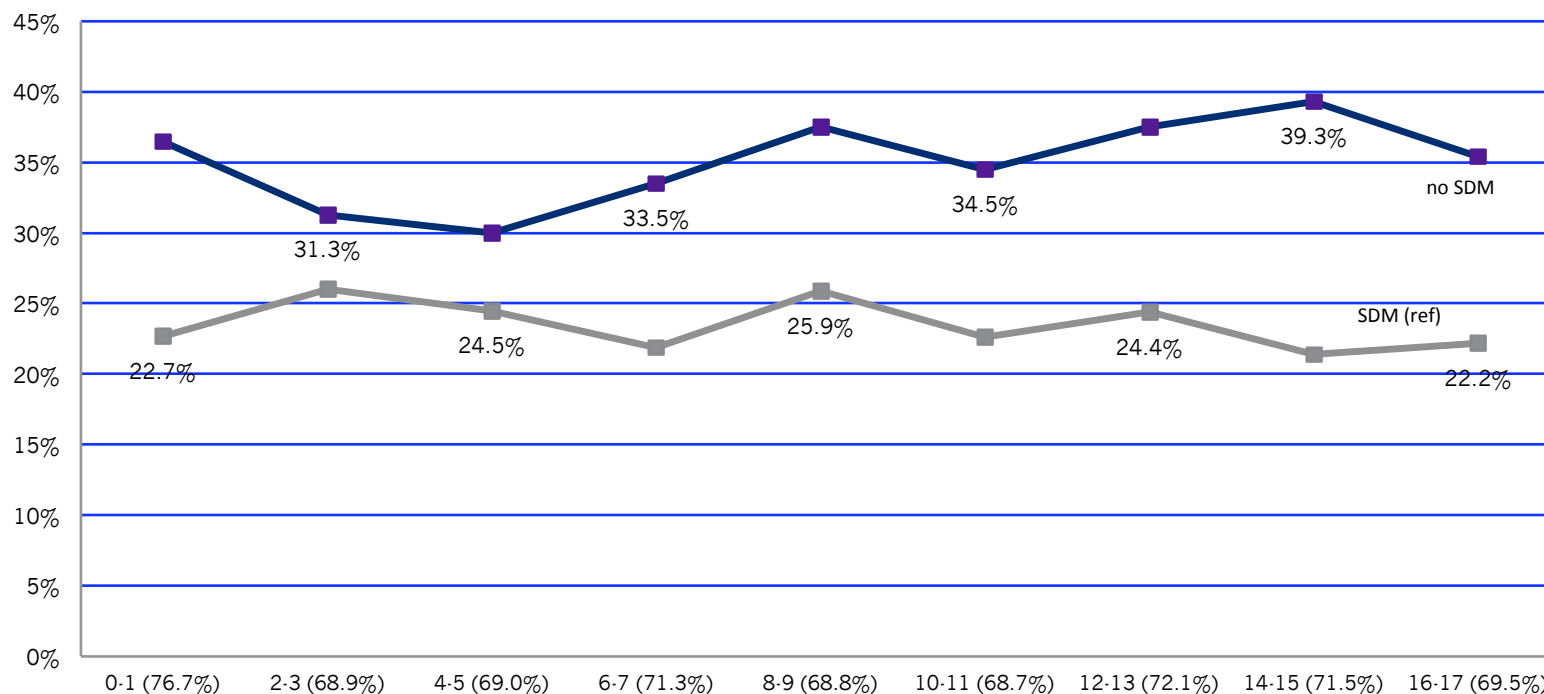
- ▶ Families have the greatest interest in ensuring that their children's and family's services meet their needs, and the most to gain in improving services and outcomes
- ▶ Parents can be powerful partners with national, state, and local agencies across systems:
 - Assessing needs
 - Planning improvement activities
 - Advocating for the resources needed to implement those activities, and
 - Evaluating results

Evidence-base for family engagement

- Correlation between level of family engagement and satisfaction with other core outcomes
 - Family engagement and family centered care --when they DO NOT occur--are highly predictive of poor outcomes on the other indicators
- Correlation between level of family involvement and educational performance
 - Family participation in education was twice as predictive of student academic success as socio-economic status
 - The more intensively families are involved (advocacy, decision-making, oversight, volunteers, support at home), the more beneficial the achievement effects

Correlation among outcomes

CSHCN whose Conditions Consistently Affect Daily Activities, Often a Great Deal by Age and Participation in Shared Decision-Making (2009/10 NS-CSHCN)



Age in years (% who met SDM)

■ Met shared decision-making

■ Did not meet shared decision-making

Age 0-3	Age 4-7	Age 8-11	Age 12-14	Age 15-17
AOR=1.11 (0.76-1.62)	AOR=1.18 (0.94-1.49)	AOR=1.15 (0.93-1.42)	AOR=1.58 (1.24-2.02)	AOR=1.40 (1.11-1.76)

Source: Bethell CD, Strickland BB, Newacheck PW, Honberg LE, Wells N, Fine A, Wilhelm CL, Antonelli R. Optimizing the CSHCN systems of care model using the life course perspective: a comparison of frameworks and national data findings. *Upcoming MCH Journal Special Issue on Life Course.*

Why partner with families?

- ▶ Families involved in decision making are more satisfied with their primary care provider
- ▶ Families active in developing a CYSHCN care plan are more likely to follow and maintain the care plan
- ▶ Families can tell you the types of small changes that will make a meaningful improvement

What is leadership?

- Leadership is an attitude and a behavior, not a position
- Leadership can be shared
- Leadership can be collaborative
- Leadership can be learned



Shared leadership is important because:



- Multiple perspectives & diverse strengths and talents are combined to achieve goals
- Families know how systems really work “on the ground”

Partnering with Families to Support Achieving & Sustaining MCH Goals

- ▶ Equity
- ▶ Access
- ▶ Accountability
- ▶ Integration
- ▶ Quality
- ▶ Life course theory
- ▶ Social determinants of health
- ▶ Health & health care
- ▶ Population-based health



- ▶ Diverse family leaders are essential partners in achieving MCH goals
- ▶ Family engagement aligns with core public health principles

Valuable Roles of Parent Leaders



- ▶ Advocate on an individual basis
- ▶ Act as a catalyst for new ideas
- ▶ Think about how systems fit together
- ▶ Help others understand how change happens
- ▶ Coordinate activities aimed at making change
- ▶ Help others work as a team
- ▶ Facilitate info sharing with decision-makers

Key Roles for Parent Leaders

- Role model for other parents
- Co-trainers
- Contributor to materials development
- Participant at conferences, meeting
- Paid consultant
- Grant reviewer
- Participant in evaluation & quality improvement activities
- Participant in needs/ strengths assessment processes
- Advocate for individuals, families, programs, system change
- Participant in focus groups
- Advisory Board or Board member
- Witness at public hearings
- Public speaker, Panelists
- Media interviewee/ spokesperson

Examples of Successful Innovative Leaderships Models

- Parent Led Trainings to FQHC's & Early Head-start Programs
- Parent Leaders enhancing community developmental screenings
- Family Resource Specialist at Department of Health Case management units
- Family Resource Specialist in Hospitals
- Parent Leader CDC Act Early Ambassador
- Community of Care Consortium Stakeholder work-groups around MCH 6 core outcomes
- Bright Futures

Research Supporting Impact of SPAN Staff & SRPs

- ▶ NJ families assisted by FRSs demonstrate documented improvements in knowledge, confidence, competence, & skills on pre-post tests using nationally validated NCSEAM surveys
- ▶ Practices with trained SPAN Medical Home parent partners demonstrated significant improvement in medical home-ness and family satisfaction with services on Medical Home Index
- ▶ Trained SRPs and Parent Partners show greatest satisfaction!

SPAN Parent Training Examples

- ▶ Education Advocacy from EI to Transition
 - ▶ Health Advocacy (including mental health/NJ Children's System of Care)
 - ▶ Parent to Parent Support Parent Orientation
 - ▶ Advocacy skills
 - ▶ **Comprehensive**
- ▶ Medical Home Parent Partner Training
 - Overview
 - Six core outcomes
 - Components & characteristics of a medical home
 - Helping families partner with health professionals
 - Role of a parent partner
 - Resources to share
 - ▶ **Training**

What does NJ Title V say about our partnership?

- Over 90% of Special Child Health Services Case Managers say that Family Resource Specialists:
 - Help families partner with their child's health, education, and other service providers
 - Help families more effectively navigate community services
 - Build parent confidence & competence in getting needed services for their child

“Our collaboration-partnership is possible and effective because we have trust in each other, equality and a balance of power, a shared vision and commitment to the same goals; we highly value the contributions made by each agency; and we see the benefits to our respective agencies, but most importantly to the families and children we serve. ” Gloria Rodriguez, Assistant Commissioner, Family Health Services, NJ Department of Health and Senior Services

What families say about SPAN's Family Resource Specialists?

- **Over 90%:**
 - **Are better able to partner with their child's provider**
 - **Are better able to navigate community services**
 - **Feel more confident in getting needed services for their child**



“When my child was diagnosed, I cried in the doctor’s office parking lot for an hour. I felt hopeless. I was sent home with a paper that had alphabet soup written on it. None of the professionals asked me if I knew what the initials meant or what family supports I had or how I was managing with my other children. None of the professionals could imagine how isolating, sad, and confusing the whole process was. It took another parent to understand and guide me. By being paired with a parent who had “been there,” and who understood my family’s unique needs, it brought out the best in me at the worst time in my life.” NJ Latina Parent helped by SPAN

What do health providers say?

- Over 90%:
 - Are better able to partner with parents
 - Are more knowledgeable about/connected to community resources for families
 - Feel more confident in coordinating health care services for CYSHCN



"I always knew I needed to partner with my patients' parents about their individual care, but it never occurred to me that parents could also help me improve my practice overall. Our parent partners are an incredible source of information and ideas. They know about the community resources in our area, and they know what parents need. They help us figure out what is going right, and what we need to improve. And they are an incredible resource for the other parents of children with special needs in our practice. I don't know how we ever lived without parent partners!" Pediatrician, NJ Medical Home Practice

“

Major Factors of Systems Change

- “Power concedes nothing without a demand; it never has and it never will.”
 - *Frederick Douglas*
- Improving systems and services requires a demand for change & accountability; informed, engaged parents can provide the most powerful support for that change & accountability

Spheres of Conflict

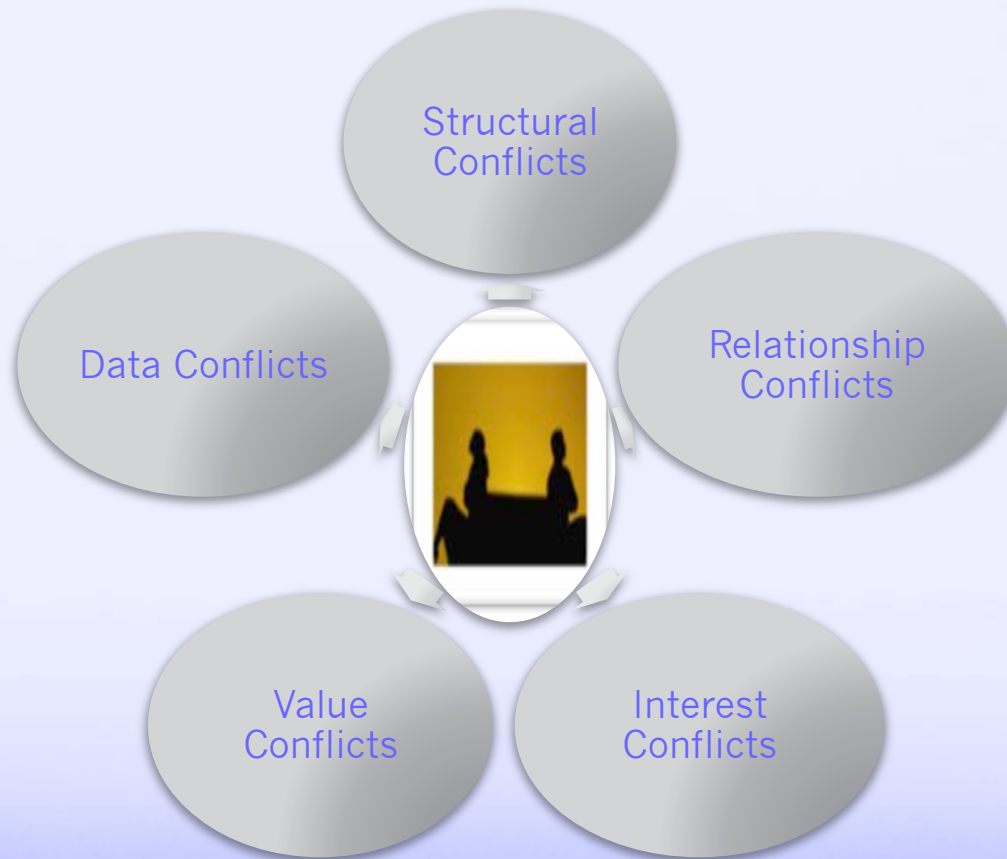
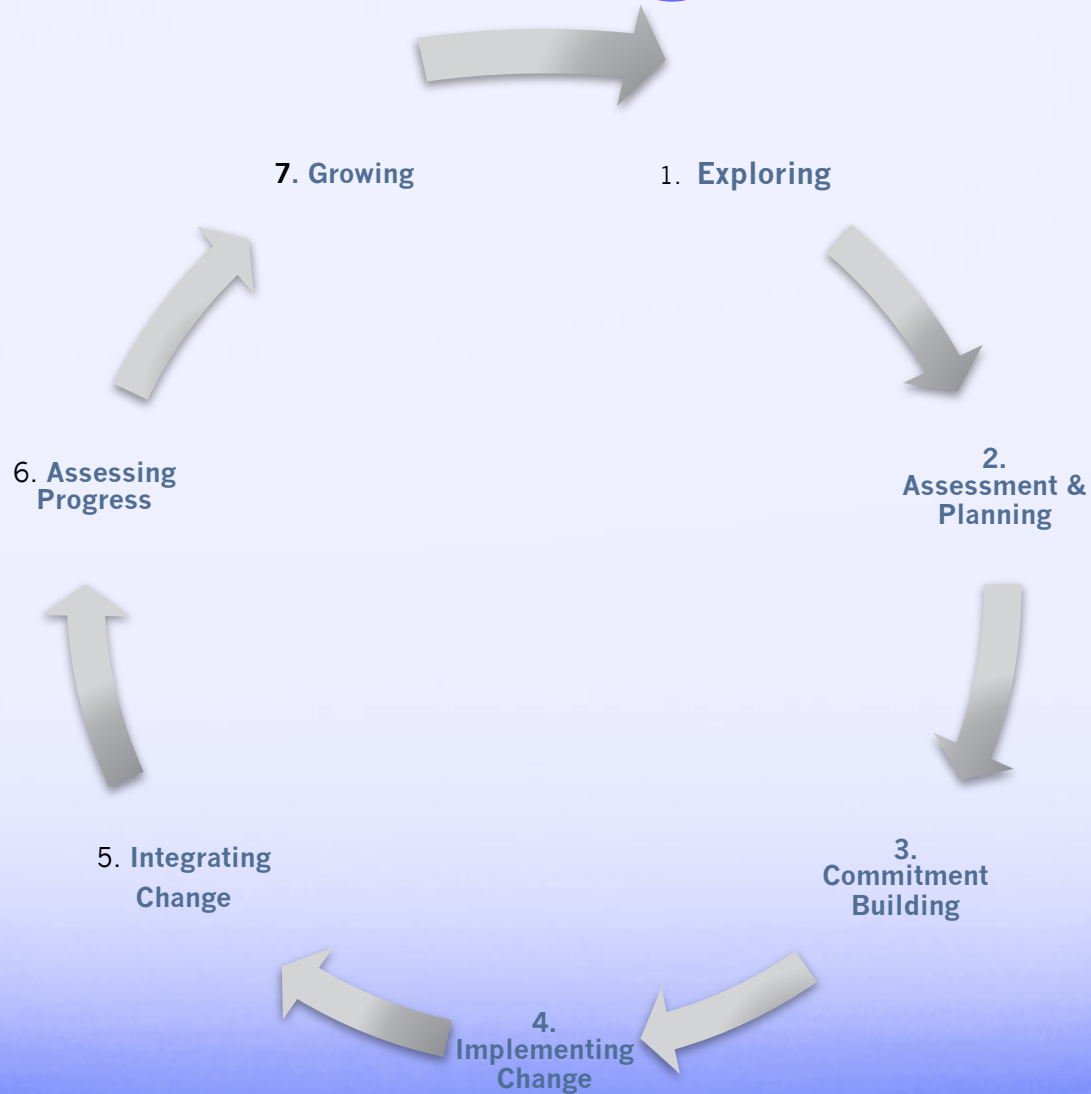


Table 1 Theorized Pattern of Relational and Conventional Bureaucratic Organizations

Components of Organizational System	Key Dimensions of <i>Relational</i> Bureaucracy	Key Dimensions of <i>Conventional</i> Bureaucracy
1. People	Staff members reflect the cultures/ languages of families served.	Staff members may not reflect the cultures/languages of families served.
2. Structures: power	Democratic and participatory structures.	Hierarchical staff structures.
3. Structures: relationships	Systems exist to support use of relational competencies for caring, flexible, and responsive approach to individual needs.	Rigid rules, boundaries, and policies exist to guide uniform approach.
4. Processes: power	Opportunities to share knowledge, expertise, and power.	Hierarchy of expertise, knowledge, and power.
5. Processes: relationships	Staff relationships are caring, reciprocal, and respectful. Relational competencies are recognized, valued, and developed.	Staff relationships are formal, hierarchical, and impersonal. Adherence to rules and protocol is recognized and valued.

The Planned Change Process



Starting place

- ▶ Identify small group of parents from targeted community & community cultural brokers
- Establish a core group of family leaders that has been oriented and trained to be on teams
 - Include parents with both successful & less successful experiences with systems
- Reinforce the commitment of valuing their continued involvement through all phases of improvement activities

How do we get there?

- ▶ Engaging diverse families requires:
 - Vision, leadership, & investment
 - Active listening & cultural reciprocity
 - Tangible, emotional, & environmental supports
 - Mechanism(s) to track the contributions & outcomes of family engagement– *“you treasure what you measure”*

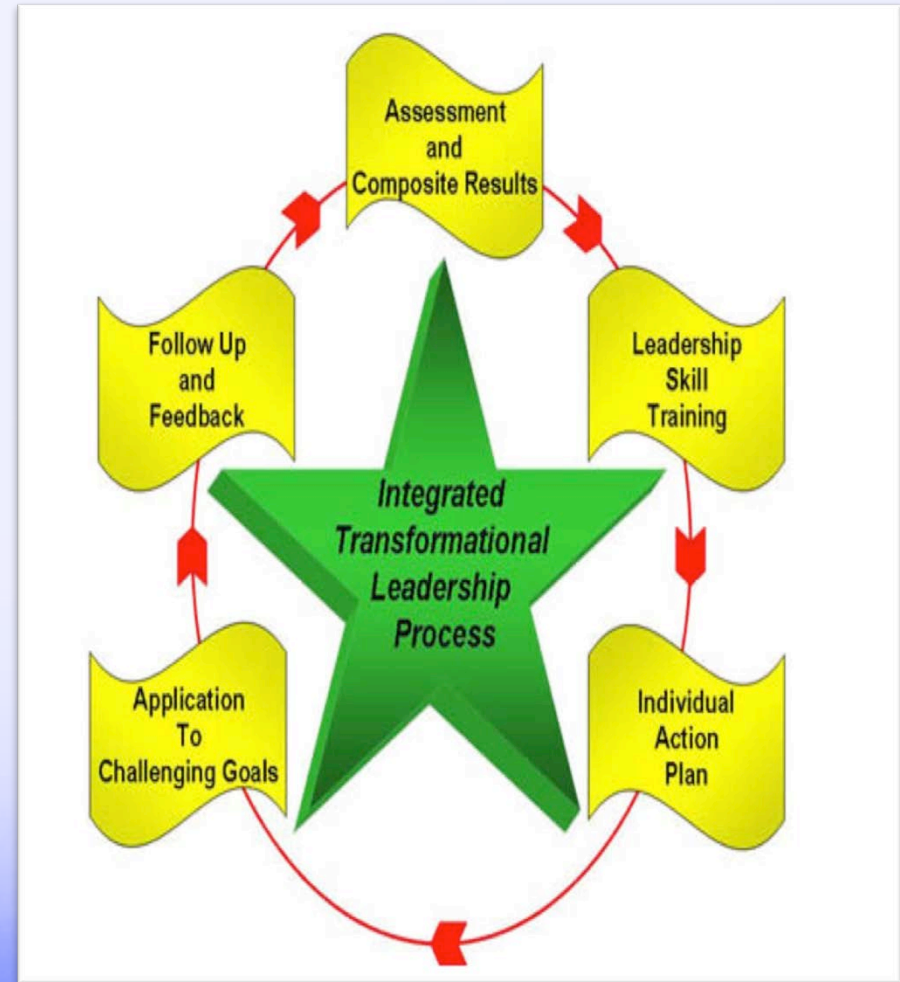


Next steps

- ▶ Recruit Leaders ..Ask for their help in:
 - Understanding cultural, language, religious impacts (both sources of strength & potential barriers)
 - Developing strategies to reach, engage, & support families from their background
 - Implementing strategies for training and growth
 - Evaluating progress & planning next steps
- ▶ Provide them with necessary supports to sustain partnerships

Pathways to Parent Leadership

- Critical supports:
 - Contact with other parents in leadership roles
 - Opportunities to take on leadership roles, however small, & safe settings to practice them
 - Relationship with respected & trusted person who provides feedback & support
 - Sense of belonging



Critical Supports

- Understanding from families “like me” / who have “been there”
- Focus on empowerment
 - Educate
 - Engage
 - Enhance effectiveness
- Share:
 - Information
 - Parent development
 - Emotional support
 - Connection to resources
 - Advocacy
 - Leadership opportunities
 - Friendship
 - Celebration

Critical Supports

- Build:
 - Trust
 - Self-confidence
 - Self-efficacy
 - Relationships
 - Support networks
- Listen for the heart, with the heart
- Communicate with honesty
- See every parent as a leader
- Start where families are, help them identify where they want to go
- Help families recognize strengths
- Lead together
 - See every parent as a leader
 - Make space for new leaders

Leadership Skills & Qualities

- Active listening
- Empathy
- Sincere caring
- Recognition & appreciation of other leaders' knowledge & skills
- Focus on strengthening knowledge & skills
- Shared decision-making
- Effective Communicators
- Team players
- Problem solvers
- Self Aware



Leaders Know Themselves



- ▶ Who am I?
- ▶ What am I doing here
- ▶ What are my:
 - Goals, purposes
 - Expectations
 - Motivations?
- ▶ What strengths & challenges do I bring?
- ▶ How can I best use my leadership skills?
- ▶ How can I make space for others?

Family Leadership Knowledge



- ▶ Laws & regulations
- ▶ How institutions work
- ▶ Key decision-makers
- ▶ Formal & informal decision-making
- ▶ Facts; current status
- ▶ Barriers & solutions
- ▶ Qualities of effective systems
- ▶ Existing resources

Why do parents get involved?



- The issue is important to them, their family, & their community
- They have something to contribute
- They believe that they will be listened to, their contributions respected, and their participation will make a difference



Why & How do Leaders stay involved?

- Multiple opportunities for participation
- The level of participation can vary as needed
- Families receive sufficient advance notice
- Family participation is facilitated
- Families are listened to; their ideas are supported & respected
- Families do not experience retribution as a result of their participation
- Family participation has an impact
- Family participation is consciously & visibly appreciated

Family Leadership Contributions

- Provide specialized expertise that may be missing from staff
- Serve as ambassadors, cultural brokers building bridges into the community
- Survey the need to enhance existing activities and outreach strategies
- Bring in resources and create awareness about programs and services
- Help conduct evaluation and oversight activities, maintain accountability

Levels of Focus for Parent Organization Partnerships

- Level 1: Strengthening individual parent knowledge & skills
- Level 2: Promoting community education
- Level 3: Educating Providers
- Level 4: Fostering coalitions & networks
- Level 5: Changing organizational practices
- Level 6: Influencing policy & legislation

Framing it as a..

Collaborative Partnership

- ▶ Shift from *servicing* families to *partnering* with families
- ▶ Shift from us vs. them to us together against a problem



Myth busting

Fear-Based Thinking	Innovative Thinking
Families are complainers	Families bring informed solutions
Don't understand the business of healthcare, budgets and systems	They are business owners too – 99% of private enterprises are small businesses
HIPPA regulations won't allow for this	Family Leaders sign confidentiality statements like any other consultant
FCC takes too much time	Efficiency is increased
Families are not available to participate	Develop contracts for equitable pay for consumer consultants
The families we work with don't care	We haven't tried hard enough

Token vs. Meaningful Parent Leadership

- No preparation or information given prior to participation
- No meaningful role in meeting or forum
- Often one time only participation
- Professionals talk “around parents” using acronyms and terminology unfamiliar to them
- Adequate notice of the meeting and material supports are provided to assist with parent attendance
- Materials and/or an orientation is provided prior to the meeting
- Parent input is valued and individuals work with parents to clarify terminology, systems and policies
- Follow-up is provided

Readiness Factors for Family & Professional Partnerships

Agencies:

- ▶ Explore past history
- ▶ Are you ready for full transparency
- ▶ Leadership support in all directions
- ▶ Willingness to be flexible
- ▶ **Your budget is your policy statement!**

Families:

- ▶ Clarify your role, expectations and accountability
- ▶ Be honest about your skills, knowledge and abilities
- ▶ Present yourself as a project consultant
- ▶ Can you represent the constituency of families beyond yourself?
- ▶ Model partnership at all levels
- ▶ **Braid experience with knowledge**



Sustainability Strategies

- Commit to cultivating family leaders
- Articulate the value statement
- Clear expectations, roles and outcomes
- Flexible scheduling and meeting formats
- Engage in inter-agency data sharing
- Assure & continue to enhance competence
- Cross-agency impact reporting
- Implement corporate leadership strategies
- Leadership vs. Management
- Family leaders bring life to your mission
- Family engagement & leadership activities embedded in ALL grant proposals

Group Activity & Report Out

- What is your action plan for involvement?
- We know the why, we need to plan the:
 - Who?
 - What?
 - When?
 - Where?
 - How?



**Together we are stronger!!
A circle of hands will receive us...**



**"You can do
what I cannot
do. I can do
what you
cannot do.
Together we can
do great
things."**

- Mother Teresa