

Engaging Families as Partners – Part 2

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DECEMBER 2, 2020

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3. Call your doctor or therapist for help

Agenda

1

Review of the core principles for meaningfully engaging families as partners

2

Principles and prerequisites for partnership with families and youth

3

Crosswalk of roles for youth and families by purpose

4

System policy and design: considerations, strategies and examples

5

Recruiting, supporting and retaining family experience and expertise in receiving services

6

Family-run organization and resources

Engaging Families as Partners in Policy:

Strengthening Services, Communities & Systems

Pat Hunt, Executive Director

Jane Walker, Senior Advisor

*Family Run Executive Director Leadership Association
December 2020*



Poll #1

Currently, what role do you have?
(pick all that apply)

- ☐ Family/parent peer support
- ☐ Youth peer support
- ☐ Peer support
- ☐ Clinician
- ☐ Medical doctor
- ☐ Supervisor/administrator
- ☐ Local/state government
- ☐ Other (please put in chat!)

Poll #2

Did you participate in Part 1 of this series?

☐ Yes

☐ No

Learning Objectives

Participants in part 2 of the series will:

- Identify core principles for meaningfully engaging families as partners
- Describe the value of partnerships for achieving policy goals
- Apply methods for recruiting, supporting and retaining family experience on governance and policy bodies
- Gain access to sample tools for strategic recruitment of families

Families Define their Members



“Call it a clan, call it a network, call it a tribe, call it a family. Whatever you call it, whoever you are, you need one. Families are big, small, extended, nuclear, and multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support.... A family is culture unto itself, with different values and unique ways of realizing its dreams; together, our families become the source of our rich cultural heritage and spiritual diversity.... Our families create neighborhoods, communities, states, and nations.”

— Polly Arango, Family Advocate and Co-founder
Family Voices, Algodones, NM (1942-2010)

“Llámalo un clan, llámalo una red, llámalo una familia. Independientemente de cómo lo llames, quién seas tú, necesitas uno. Las familias son grandes, pequeñas, extendidas, nucleares y multigeneracionales, con un padre, dos padres y abuelos. Vivimos bajo un mismo techo para muchos. Una familia puede ser tan temporal como unas pocas semanas, tan permanente como para siempre. Pasamos a ser parte de una familia por nacimiento, adopción, matrimonio o por un deseo de apoyo mutuo ... Una familia es cultura única, con diferentes valores y formas únicas de concretar sus sueños; juntas, nuestras familias se transforman en la fuente de nuestro rico legado cultural y diversidad espiritual... Nuestras familias crean vecindarios, comunidades, estados y naciones”.

— Polly Arango, defensora familiar y cofundadora de Family
Voices (Voces Familiares), Algodones, NM (1942-2010)

Which families are we talking about today?

- Lived experience in raising and being responsible for a child or youth with behavioral health needs
- Experience with child serving systems
- Seasoned wisdom and current experience

Why this Topic?

Policy-makers, researchers and practitioners increasingly understand family engagement as an evidence-informed best practice and as an integral component of the ideal model of service delivery.

(Chovil, 2009; MacKean et al., 2012; Manion & Smith, 2011)

Why Involve Families of Children & Youth Who Receive Services?

We rely on families because they –

- Families have first-hand knowledge of what works, what doesn't and what's missing for them
- Cross the bounds of culture
- Are unique resources - perspective

“When patients and families are partners in planning and making decisions about their care, health outcomes are better, patient experience and satisfaction improves, and often, costs are lower.”

Why Involve Families of Children & Youth Who Receive Services?

Customer voice –

- Improves products
 - New components for current products
 - Greater utility
- Drives market change
 - New funds for quality products
 - New products with current funding
- Greater customer satisfaction
- Brand loyalty

It is good business practice to include product users in design, development, promotion, and quality feedback!

Involvement > Engagement

<https://tats.ucf.edu/wp-content/uploads/sites/9/2018/03/05.2-parent-engagement-head-start.pdf>

Examples that illustrate the shift

PARENT INVOLVEMENT

- Parent Involvement is primarily the responsibility of family services staff (or parent involvement specialists, home visitors, or transition specialists)
- Parent involvement might revolve around outputs—for example, the number of parents who show up at a meeting.
- Parent involvement works with a small % of families involved in leadership opportunities (policy council, parent meetings, special events)
- Programs that involve parents collect data from children and families—for example, information about parent participation.

FAMILY ENGAGEMENT

- ▶ Family engagement is embedded in the work of all staff members, management systems and leadership priorities.
- ▶ Family engagement focuses on evidence of positive, goal directed relationships, for example, that result in family progress in one (or more) of the seven outcome areas.
- ▶ Through ongoing relationships, family members are engaged in a variety of goal directed ways related to Parent and Family Engagement Outcomes.
- ▶ Programs that engage families use child and family data to improve services. These programs help families understand and use child data to support their children's progress and development.

Involvement > Engagement > Partnership

- Redefines the relationships in healthcare by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings.
- In patient- and family-centered care, patients and families define their “family” and determine how they will participate in care and decision-making.
- A key goal is to promote the health and well-being of individuals and families and to maintain their control.

Poll #3

Do you have strategies for achieving partnership with families in policy groups?

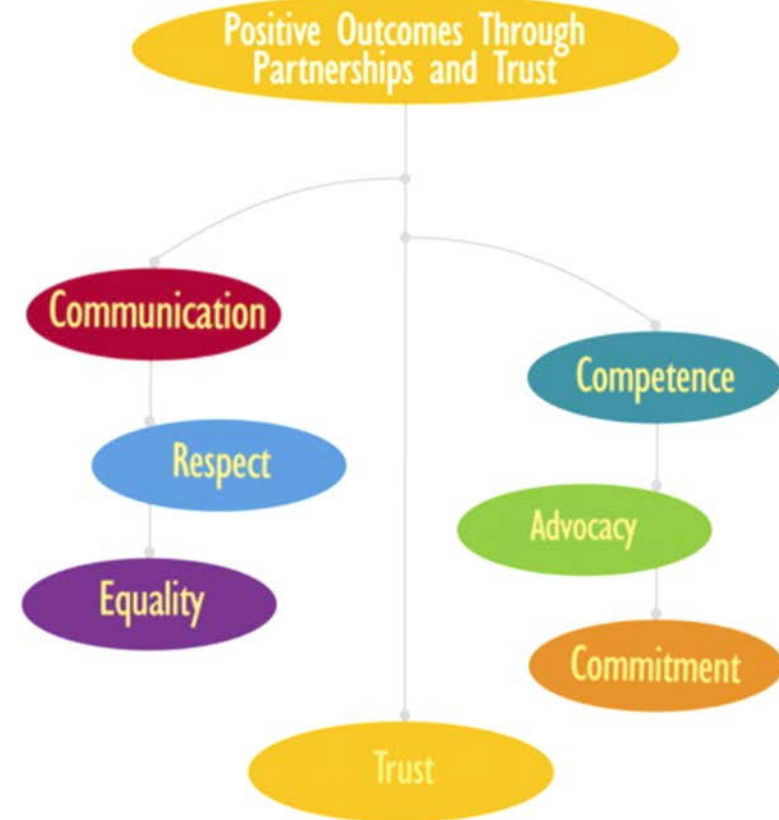
(select best match, use chat to describe strategies)

-
- ☐ Yes, well developed
 - ☐ Somewhat developed
 - ☐ We just started
 - ☐ I'm not sure
 - ☐ None

Principles for partnerships with families

Turnbull, A.P., Turnbull, H.R., Erwin, E., and Soodak, L., Shogren, K. (2015). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust* (7th ed.). Boston, MA: Merrill/Prentice Hall.

Families, Professionals, and Exceptionality



Seventh Edition

Ann Turnbull | Rud Turnbull | Elizabeth J. Erwin | Leslie C. Soodak | Karrie A. Shogren

Prerequisites for partnership

- Commitment of leadership
- Commitment of resources – funds
- Commitment of staff time – training and meaningful engagement
- Not responsibility of one person or one department – shared responsibility
- Written policies and procedures
- Not an add-on

Value of Family Partnership

Changes

- Institutional culture
- Institutional practice

Builds

- Awareness, understanding & self-efficacy
- Sense of community
- New practices & policy for better servicing youth & families

Improves

- Individual outcomes
- Organizational outcomes

Informs

- Resource realignment & service development
- Research & evaluation
- Public policy

TRANSFORMS

Engaging Families

- Establish relationships
- Know the type of experience you are seeking
- Develop a plan & process that includes families
- Provide necessary supports
- Identify & employ retention strategies

Roles for Youth and Families: Purpose

Inform	Consult	Involve	Collaborate	Empower
Websites	Focus Groups	Co-Lead Workshops	Advisory Groups	Strategy Groups
Information Repositories & Kiosks	Surveys	Present at Conferences	Networking & Peer Support	Steering Committees
Media Releases	Face-to-face Interviews	Serve as Expert Panelist	Support Groups	Decision-making
Feature Stories	Public Meetings & Forums	Facilitate Groups	Family Advisory Councils	Hired in Staff Roles or Peer Roles
Fairs & Events	Suggestion Boxes	Development, Review and Dissemination of Materials/Products	Youth Advisory Councils	Leaders in Youth Movement & Family Movement
Open Houses	Interviews		Liaison to Provider and Policy Groups	
Fact Sheets, Brochures, and Leaflets	Patient Experience Trackers			



Hart's Ladder of Participation



1. Youth and Family **Initiated and Directed**
2. Youth and Family Initiated, **Shared Decisions with Adults and Partners**
3. Youth and Family and Adult/Partner Initiated and Directed
4. Adult/Partner Initiated, Shared Decisions with Youth and Family
5. Consulted and Informed
6. Assigned and Informed
7. Tokenism
8. Decoration
9. Manipulation

Adapted from Hart, R. (1992). Children's Participation from Tokenism to Citizenship. Florence: UNICEF Innocenti Research Centre, as cited in www.freechild.org/ladder.htm

Be Prepared

- Work with families or a family-run organization to develop a one page marketing tool
 - ✓ Include key messages about the purpose, why families are necessary members
 - ✓ Brief description of group composition, duration, expectation
 - ✓ Frequency of meetings
 - ✓ Real time commitment you are looking for
 - ✓ Scope and authority of the group (advise, set standards, establish or influence, oversee, etc.)
- Understand that things impact the ability of families to fully participate
- Be strategic in recruiting, supporting and retaining families in policy work
- Know what to access & what to avoid

A background image showing a woman and a child looking at a wall with various papers or photos pinned to it. The image is overlaid with a blue gradient.

Family-Run Organizations

A Valuable Resource

Monthly Minute: Family Run Organizations - YouTube

https://www.youtube.com/watch?v=L2JKFaDBhDE&list=PLWv-X8-WjcQXJmRQ6ySK2mABg_aOwNgVx&index=11

Successful Policy Groups

- *Unified* understanding of the mission
 - ✓ Historical context
 - ✓ Distinct scope of authority & influence
- Individual & collective commitment to the mission
- Members have a collective role vs. personal or agency agenda
- Individual experience of members is connected to a broader constituency
- Prepared to work in partnership

Policy & System Design: *Points to Ponder*

- Include families with varied experiences and from diverse cultures
- Family run organizations are essential for preparing and supporting family engagement
- Policy groups can benefit from training and support in how members can work effectively together

Policy & System Design: *Strategies*

- Institute by-laws and develop targeted recruitment strategies based on desired experience
- Identify the scope of authority and responsibility of the governance body
- Recruit multiple families
- Appreciate and celebrate accomplishments

Policy: Examples

- At least 51% vote on governing bodies
- As members of teams to draft legislation
- Testifying and sharing their experiences with legislators
- As members of system design workgroups and advisory boards
- Raising awareness as speakers and participants in public awareness campaigns

A woman with blonde hair tied back is smiling and talking on a black mobile phone. She is wearing a light blue button-down shirt. The background is a blurred office environment with shelves and papers. The entire image has a blue overlay.

Recruiting Families

Laying the Groundwork

- Know the type of experience you are looking for – based on mission/task and group composition – develop a plan
- Set clear expectations for participation
- Family members in formal roles (chair, co-chair, etc.)
- Operations are transparent

Recruitment Strategies

- Use direct and indirect methods for reaching folks
- Establish relationships with family organizations
- Determine if the local culture aligns w/the mission/focus
- Invite people as *observers* to prepare them for future membership
- Peers to perform outreach



Supporting Families in Policy Work

An Atmosphere that Supports Participation

- Welcoming, respectful and safe environment (includes greeting process, room setup, commitments to safety, etc.)
- Physical and emotional comfort – getting to know more about other members
- Clear roles & agenda
- Peers “at the table” – Develop collaborative working relationships
- Use real words – avoid acronyms, labels and slang
- Create a sense of acceptance, validation and appreciation

Other Supports to Consider

- Tangible (stipends, transportation, meals ---> internet service, smart phones, hot spots)
- Accommodations (font used, diet, chemical sensitivities)
- Orientation materials and process
- Clear protocols for committee operations
- Support member skills to enhance effectiveness of participation
- *Peers --- provide a “buddy” to help potential members learn about the work and the group before they join*

Poll #4

What support(s) does your organization provide for families who are partners in policy?

- ☐ Orientation when families join a committee or workgroup
- ☐ Opportunities for training
- ☐ Travel reimbursement
- ☐ Childcare reimbursement
- ☐ Other (please put in chat!)

A woman with blonde hair tied back is smiling and talking on a black mobile phone. She is wearing a light blue button-down shirt. The background is a blurred office environment with shelves and papers. The entire image has a blue overlay.

Strategies for Retaining Families as Members of Policy Groups

A woman with blonde hair tied back is smiling and talking on a black mobile phone. She is wearing a light blue button-down shirt. The background is a blurred office environment with shelves and papers. The entire image has a blue overlay.

Please use the chat box to tell us what has made you want to leave a group.

Helping Members Stay Involved

- Ensure families receive information in a timely manner
- Share information in necessary languages and formats
- Families help translate data – provide it in easy-to-understand format
- Prevent groups from experiencing inertia
- Recognize contributions and celebrate accomplishments

Plan for Turnover

- Know that families can participate in various ways, for different durations of time and may face things that can interrupt their commitment
- Be prepared to address turnover
- Leave the door open for other possibilities
- It's ok to leave - Reinforce appreciation and accomplishments

Consider Culture





Tools for Supporting Policy Groups

Resources

- ✓ **Family Engagement in Systems Infographic:**
<https://www.fredla.org/wp-content/uploads/2019/12/Family-Engagement-v8-1.pdf>
- ✓ **Tip sheet on strategies for reaching families:**
https://www.fredla.org/wp-content/uploads/2015/09/Outreach-to-Families_FREDLA-2016.pdf
- ✓ **Family Voice on Councils & Committees (FAM-VOC) Assessment Tool** – contact Malisa Pearson at mpearson@fredla.org
- ✓ **Supporting Family Participation in Systems of Care:**
<https://www.fredla.org/wp-content/uploads/2018/06/SupportingFamily-2017-Revised2018-newlogo-print-1.pdf>

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THANK YOU!

FREDLA Team

The slide features a light blue horizontal band across the middle. Above and below this band are several triangles in blue, purple, and magenta, some pointing left and some right, creating a modern, abstract design.

Questions?



Thank you!

MAGELLAN CONTACT INFORMATION

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About the presenters



Pat Hunt is the executive director of FREDLA, the national Family Run Executive Director Leadership Association, a non-profit union of leaders of grassroots family-run organizations across the nation. Along with her lived experience as a parent, Pat brings over 25 years of experience promoting and advancing positive outcomes for children with behavioral health needs and their caregivers. During this time, she had extensive experience overseeing both federal and state grants and served as the founding director of a family-run organization.

Pat has provided technical assistance in 42 states regarding policy issues that affect children's behavioral health. Her skilled facilitation has helped families, state and local leadership develop and sustain best practices through local systems of care for children, adolescents and their families. Her leadership at a Managed Care Organization advanced national recognition and solution building in arenas such as the appropriate use of psychotropic medication with children and youth, and with outcomes and efficiencies associated with preventing undue reliance on out-of-home care.

Pat's experience includes over 10 years in a corporate leadership role at Magellan HealthCare to advance best practices for children, youth and their families and to ensure that their experiences informed policies, practices and program development. She previously held a senior leadership position as a conduit for local grassroots experience to inform national policy decisions at the Federation of Families for Children's Mental Health. The foundation of her career was built on personal experience and the delivery of parent support. Pat has served as a VISTA Volunteer; directed a three year federally funded rural substance abuse prevention project; managed a statewide family-run organization, served as president of the Maine's mental health planning council and was the only non-state employee member invited to the Governor's Children's Cabinet.

Pat served as a member of the steering committee for Georgetown University's Communities Can Leadership Academy and as faculty to several Policy Academies & Training Institutes. Pat was appointed by the President of Maine's Senate to a Legislative committee charged with oversight of landmark legislation for children and youth with behavioral health challenges and is a past nominee for both the Robert Wood Johnson and Lewis Hine Awards for Service to Children and Youth.

About the presenters



Jane Walker, MSW is a founder and for six years served as the first executive director of the Family-Run Executive Director Leadership Association (FREDLA). Ms. Walker now serves as senior advisor to the organization. Prior to FREDLA, Ms. Walker was the founder and former executive director of the Maryland Coalition of Families for Children's Mental Health, the statewide family network in Maryland. She brings 30 years' experience in the non-profit world and most importantly 30 years caring for her daughter, Cathy, who experienced mental health challenges at a very young age. In 1999, the Mental Hygiene Administration in Maryland provided funding to establish a statewide family organization. Jane was hired as the first executive director and from one person grew the organization to a 45 family member staff who provide peer-to-peer support to other families in similar situations. Ms. Walker was also one of the founders of the National Federation of Families for Children's Mental Health and served as the president of the board from 1993-95. Ms. Walker has a Bachelor's Degree from the University of Maryland Baltimore County and a Master's Degree in Social Work from the University of Maryland School of Social Work and is the recipient of numerous awards for her leadership and advocacy.



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