

Framework for Assessing Family Engagement in Title V Programs



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Objectives

- Learn about a framework to promote Title V/Family Partnerships across all 5 MCH population domains
- Learn from each other about State Title V-Family Partnerships that exemplify one or more key criteria from each of the 4 family engagement domains
- Provide/share resources to promote family engagement

Family Voices



www.familyvoices.org

Framework for Family Engagement



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Issue Brief: A Framework for Assessing Family Engagement in Systems Change

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Abstract

Families of children and youth with special health care needs (CYSHCN) have unique perspectives about the complexities of systems of care because they are involved with so many aspects of these systems. As their children's primary caregivers, families are deeply affected by systems-level issues, such as care fragmentation, which are often a direct result of ineffective or outdated health care policies and practices.¹ Families' lived experiences make them uniquely qualified to partner in shaping systems-level policies that can improve systems of care for all children, especially CYSHCN.^{2,3,4,5,6}

<https://www.lpfch.org/publication/framework-assessing-family-engagement-systems-change>

Lit Review & Key Informant Interviews

FAMILY VOICES
Literature Review
Framework for Assessing Family Engagement

VISION

Introduction

Families of children and youth with special healthcare needs (CYSHCN) best understand the issues and complexities of care systems because they are involved with all aspects of these systems. As their children's primary caregivers they are personally affected by systems issues. This unique experience makes families key partners in shaping healthcare policies and programs (HRET, 2015; Kuhlthau et al, 2011; Funchess, Spencer & Niarhos 2014; Howrey et al, 2015; Reynolds et al, 2015).

As home to the National Center for Family/Professional Partnerships, Family Voices is an integral component of the Maternal-Child Health Bureau's commitment to authentic patient and family engagement (Krauss et al, 2001; Anderson & Wells, 2005; Wells & Anderson, 2006; AMCHP, 2016) and a long history of efforts undertaken to understand and implement elements of family engagement at the systems level to improve services, programs and policies around children's health. For this literature review, we draw on literature from a variety of sources, within and without the maternal-child health community, including peer-reviewed articles and grey literature reports. The articles and reports reviewed represent wide ranging and sophisticated approaches to patient and family engagement being practiced today, and provide a picture of a vibrant and increasingly evidence-based field of study.

Healthcare systems serving children and youth with special healthcare needs will support effective strategies that place the family at the center of all levels of healthcare and will be strongly committed and prepared to work collaboratively with families to implement

HealthInsurer
LEND
Medicaid
HospitalStaff
GovernorAppointedAdvisoryCommittee
TitleV FamilyLeaders DPH
RGNProfessionals
FamilytoFamilyHealthInfoCenter
PediatricProviders
SteeringCommittee

Systems-level Initiatives

- 1) Policies
- 2) Programs
- 3) Practices
- 4) Services

Title V Systems-level Initiatives

- **Policy:** Title V engaged family leaders to develop policies to improve supports for children, 0 to 3, in daycare
- **Program:** Title V engaged families in sustaining its Youth Advisory Council
- **Practice:** Title V & family-led organization share data to advocate for needed services
- **Service:** Title V & family-led organization worked together to write a grant to support respite services

Source: Family Voices Data Collection System, 2018: Examples of Title V Systems-level Initiatives. Data collected from Family-to-Family Health Information Centers

Family Engagement

Authentic partnership between professionals and family leaders who reflect the diversity of the communities they represent, working together at the systems level to develop and implement better policies, programs, services, and practices.

4 Domains of Family Engagement

- 1) Impact
- 2) Commitment
- 3) Representation
- 4) Impact

Domain 1: Commitment

- 1) All partners (family leaders and organization staff) make themselves available to work together in good faith towards accomplishing a systems-level initiative.
- 2) Family engagement is promoted as a core value of the organization.
- 3) Family engagement is explicitly included as part of systems-level initiatives that impact the organization's policies, programs, practices, services, or other initiatives.

Commitment: Key Criteria

Does the organization:

- Provide mentoring/supports to ensure families understand their role and can participate as fully as possible?
- Engage families in developing its strategic plan, mission statement, grant applications, and other programmatic documents (example Block Grant Application/Report)?
- Describe family contributions in written reports, and other publications?

Commitment: Strategies & Resources

Provide mentoring/support to ensure families understand their role and can participate as fully as possible.

- **Strategies**

- If have family members on staff, match them with the families to support them in their partnership role
- Engage at least two families in the initiative
- Engage a family-led or community-based organization to provide peer-supports & skill-building workshop so all participants understand their roles

- **Resources**

- [Creating a Culture of Family Engagement in Title V MCH and CYSHCN Programs](#) (AMCHP, 2016)
- [Levels of Family Engagement in Title V MCH and CYSHCN Programs](#) (AMCHP, 2016)
- [National Center on Parent, Family, and Community Engagement](#) (Women/Maternal Health)
- Big Brothers Big Sisters of America (Adolescents) NOTE: the link is www.bbbs.org. You'll have to enter it manually. When I insert the link, it does not work.
- [Family Voices State Affiliate Organizations/Family-to-Family Health Information Centers](#) (Families of CYSHCN)

Commitment: Strategies & Resources

Engage families in developing the strategic plan, mission statement, grant applications, and other programmatic documents.

- **Strategies**

- Share info about focus groups, public forums, meetings, surveys, etc on websites & social media
- Ask all Title V programs, family-led or community-based organizations to help distribute surveys, share on social media, and to help identify and recruit families to participate in systems-level initiatives
- Work with cultural brokers or specific cultural groups

- **Resources**

- Work with the [Family-to-Family Health Information Center or Family Voices State Affiliate Organization in your state](#)
- [School-based Health Alliance](#)
- [National Association of Community Health Centers](#)
- [State Office of Minority Health](#)
- [Children's Hospital Association](#)
- [National Partnership for Action to End Health Disparities](#)

Commitment: Strategies & Resources

Describe family contributions in written reports, and other publications.

- **Strategies**

- Hire family members as Title V staff
- Contract with family-led or community-based organizations to lead or partner on grant activities
- Involve families in focus groups, surveys, and other activities associated with the needs assessment
- Describe partnerships with individuals/ families/family-led organizations in the Title V application/annual report

- **Resources**

- [Title V Maternal & Child Health Services Block Grant To States Program Guidance & Forms for the Title V Application/Annual Report](#)
- [Title V Information System](#) (TVIS)

Domain 2: Transparency

Occurs when the organization clearly documents and communicates about how it:

- 1) Identifies the issues encountered by the children and families they serve.
- 2) Supports and engages families as leaders in the organization's policy, program, service, or practice initiatives.
- 3) Ensures that family leaders can easily access and understand the information they need to participate effectively in systems-level initiatives.

Transparency: Key Criteria

Does the organization:

- Conduct specific activities to understand the issues faced by the children and families they serve?
- Provide skill-building opportunities (for example group process, goal setting, uses of data) to support all participants in their partnership roles?
- Provide specific training to ensure all participants learn to recognize, understand the impact of and reduce personal biases?
- Provide materials (for example meeting minutes, policies) in plain language (for example acronyms are spelled out, jargon is explained)?
- Ensure meeting times and locations are convenient for family leaders?

Transparency: Strategies & Resources

Conduct specific activities to understand the issues faced by the children and families they serve.

- **Strategies**

- Needs assessments
- Focus groups
- Surveys
- Consult with family-led and community-based orgs
- Consult with SPRANS & other HRSA-funded projects

- **Resources**

- [HRSA MCH Programs & Initiatives](#)

Transparency: Strategies & Resources

Provide skill-building opportunities to support all participants in their partnership roles.

- **Strategies**

- Make time to convene all partners to develop/review leadership skills
- As needed/requested, provide leadership training for family partners

- **Resources**

- [National Center for Family/Professional Partnerships](#)
- [Building Partnership Skills](#)
 - Serving on Groups
 - Leading by Convening
- [AMCHP Family Scholars Program](#)

Transparency: Strategies & Resources

Provide specific training to ensure all participants learn to recognize, understand the impact of and reduce personal biases.

- **Strategy**

- Encourage all participants to participate in Project Implicit

- **Resource**

- [Project Implicit](#)
- [National Center for Cultural Competence Self-Assessments](#)

Transparency: Strategies & Resources

Provide materials in plain language (for example acronyms are spelled out, jargon is explained).

- **Strategies**

- Use Person First Language
- Use Plain Language
- Ensure materials are culturally and linguistically competent
- Avoid jargon
- Limit use of acronyms & spell out and explain when used

- **Resources**

- [National Center on Birth Defects and Developmental Disabilities](#)
- [Centers for Disease Control and Prevention](#)
- [CDC Plain Language Resources](#)
- [National Center for Cultural Competence](#)
- [Acronym Finder](#)

Transparency: Strategies & Resources

Ensure meeting times and locations are convenient for family leaders.

- **Strategies**

- Use polls
- Provide call in phone numbers
- Use online platforms (FaceTime, Facebook video chat)

- **Resources**

- [Survey Monkey](#)
- [Doodle](#)

Domain 3: Representation

Occurs when family leaders reflect the diversity of the community served by the organization when they represent their community in systems-level activities.



Representation: Key Criteria

Does the organization

- Collaborate with a family-led or community-based organizations to recruit family partners?
- Engage family partners who are representative of the
 - Races and ethnicities
 - Cultures
 - Languages
 - Disabilities
 - Ages
 - Genders
 - Geographic area served by the organization?

Representation: Strategies & Resources

The organization collaborates with family-led and community-based organizations to recruit family partners.

- **Strategies**

- Reach out to partner organizations for suggested strategies and recommendations

- **Resources**

- Work with the [Family-to-Family Health Information Center or Family Voices State Affiliate Organization in your state](#)
- [School-based Health Alliance](#)
- [National Association of Community Health Centers](#)
- [State Office of Minority Health](#)
- [Children's Hospital Association](#)
- [National Partnership for Action to End Health Disparities](#)
- [Sustaining and Diversifying Family Engagement in Title V MCH and CYSHCN Programs](#) (AMCHP, 2016)
- [Growing Your Capacity to Engage Diverse Communities: Working with Community Liaisons and Cultural Brokers](#) (Family Voices, 2009)
- [Positive Youth Development and Engagement](#) (AMCHP)
- [Success Story: Accelerating Successful Youth Engagement in Wyoming](#) (AMCHP)

Representation: Strategies & Resources

The organization ensures family partners reflect the diversity of the population served.

- **Strategies**

- Use internal data
- Use state survey data

- **Resources**

- [US Census Bureau American Community Survey](#)
- [Kaiser Family Foundation State Health Facts](#)
- [National Survey of Children's Health](#) (children, youth, CYSHCN)
- [2018 KIDS COUNT Data Book](#)

Domain 4: Impact

Describes the areas where family leaders' ideas and views were incorporated at the systems level to improve policies, programs, practices, and services.

Impact: Key Criteria

Does the organization:

- Engage family partners in choosing goals for systems-level initiatives?
- Engage family partners in implementation of systems-level initiatives?
- Engage family partners in evaluation of the new policy, program, practice, or service?
- Make decisions based on family partners' ideas?
- Explain how policies, programs, practices, or services have changed because family partners were engaged in the initiative?

Impact: Strategies & Resources

- **Strategies**

- Bring people together to work on issues they care about.
- Let people choose what has value for them.
- Engagement depends on participants seeing value in the activity and feeling that they are contributing in meaningful ways.

- **Resources**

- Leading by Convening (LbC): 4 Simple Questions

Source: Cashman, J., Linehan, P., Purcell, L., Rosser, M., Schultz, S., & Skalski, S. (2014). *Leading by convening: A blueprint for authentic engagement*. Alexandria, VA: National Association of State Directors of Special Education.

Impact: Strategies & Resources

DEFINING OUR CORE

We are _____

who are united in _____.

To accomplish this we _____

_____.

We know we are having an impact when _____

_____.

Source: Cashman, J., Linehan, P., Purcell, L., Rosser, M., Schultz, S., & Skalski, S. (2014). *Leading by convening: A blueprint for authentic engagement*. Alexandria, VA: National Association of State Directors of Special Education.

Impact: Strategies & Resources

SAMPLE

DEFINING OUR CORE

We are a committed collaboration of stakeholders.

We are united in improving the lives of youth with disabilities beyond high school.

To accomplish this we use an active and consistent interagency approach that includes all stakeholders.

We will know that we are making progress when our change in practice results in a measurable increase in youth outcomes.

(South Carolina Community of Practice on Transition, 2013)

Source: Cashman, J., Linehan, P., Purcell, L., Rosser, M., Schultz, S., & Skalski, S. (2014). *Leading by convening: A blueprint for authentic engagement*. Alexandria, VA: National Association of State Directors of Special Education.

Impact: Strategies & Resources

The organization engages family partners in choosing goals for systems-level initiatives.

- **Strategies**

- Create a culture of collaboration

- **Resources**

- LbC Group Change: Toward a Culture of Collaboration

Source: Cashman, J., Linehan, P., Purcell, L., Rosser, M., Schultz, S., & Skalski, S. (2014). *Leading by convening: A blueprint for authentic engagement*. Alexandria, VA: National Association of State Directors of Special Education.

Thanks!



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