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Practice Summary & Implementation
Guidance

Washington Statewide Leadership Initiative Coalition

The Washington Statewide Leadership Initiative (WSLI) is a coalition that serves as a hub for family organizations, nonprofits, and professionals who provide peer support, family navigation, leadership development, and advocacy training to families of CYSHCN.



Location

Washington



Topic Area

Family/Youth Engagement



Setting

Community



Population Focus

CYSHCN



NPM

NPM 6: Developmental Screening, NPM 11: Medical Home, NPM 12: Transition



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Section 1: Practice Summary

PRACTICE DESCRIPTION

Family engagement and leadership is a foundational value of Title V with a long history of support and commitment from CYSHCN programs. The WSLI coalition uses collective impact as a framework to provide cross systems coordination of leadership trainings and connections to opportunities for family advocates at the personal, local, state, and national levels. A business analysis was done to critically assess family engagement within the State Title V MCH program to address areas of strengths and opportunities for improvement. A coalition coordinated in partnership with other Title V funded partners has increased the pool of trained families to better represent the state's cultural and geographically diverse populations.

The Washington Statewide Leadership Initiative (WSLI) is a coalition that serves as a hub for family organizations, nonprofits, and professionals who provide peer support, family navigation, and leadership development and advocacy training to families with Children and Youth with Special Health Care Needs (CYSHCN). In addition, the State Title V CYSHCN Program and the Family to Family Health Information Center provide support to many state and local nonprofit organizations who support families to help them increase collaboration, understand MCH systems building, and maximize their collective resources.

CORE COMPONENTS & PRACTICE ACTIVITIES

The main goal of WSLI is to connect families of CYSHCN to well-functioning, culturally competent systems of care, Title V National Outcome Measure #17.2. Title V MCH priorities and indicators play a vital role, including the six core outcomes for CYSHCN¹:

1. Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.
2. CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.
3. Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need.
4. Children are screened early and continuously for special health care needs.
5. Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination.
6. Youth with Special Health Care Needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.



The Washington State Title V CYSHCN Program partnered with the MCH Workforce Development Center to offer a series of Results-Based Accountability trainings around the state to family led organizations such as Parent to Parent, and their community partners. WSLI has been utilizing continuous quality improvement methodologies to identify ways to continue to move the work forward as well as to identify data sources and useful metrics. For example, our WSLI website⁵ uses web analytics to measure traffic on the site, where visitors are located, and what content is of interest. When we share a partner’s event or opportunity, we share each item linked to the partner site, increasing viewership to their work. We can monitor the links and identify areas of interest, as well as share the data with partners regarding items that bulletin readers are interested in and engaged with. Those WSLI partners which are contracted with our program are asked to complete web analytics and to complete PDSAs around outreach to rural and underserved areas of the state and reach more diverse communities. We continue to have a large representation of families and organizations from King County, our largest county and home to Seattle, and there have been efforts by multiple partners to increase participation from other parts of the state using our bulletin and website analytics.

WSLI is grounded in a Public Health approach, utilizing Title V as a convener. The State Title V Program’s Family Engagement Coordinator, in partnership with our F2F coordinators, facilitates, and convenes the Steering Committee meetings, collaborate and serve as our backbone support. WSLI Steering Committee Members collectively meet and reach decisions regarding the direction and activities of the coalition as a whole, providing collective ownership for each organization and individual involved.

WSLI uses the Collective Impact framework³. This framework synthesized practices from coalition efforts and found five key factors that drive successful coalitions:

Core Components & Practice Activities		
Core Component	Activities	Operational Details
Common Agenda or Goal	<ul style="list-style-type: none"> Collectively created and revised mission, vision, and values statement Collectively created goals 	Common Agenda or Goal
Shared Measurement System	<ul style="list-style-type: none"> Results-Based Accountability framework Evaluation Workgroup Current & Planned Work: <ul style="list-style-type: none"> Collective creation of outcome measures Baseline metrics 	Shared Measurement System



	<ul style="list-style-type: none"> ○ Performance and population-based outcomes 	
Mutually Reinforcing Activities	<ul style="list-style-type: none"> ● Steering Committee meetings ● Annual Summit ● Special Projects ● Sharing trainings and leadership opportunities ● Trainings to support family led organizations to understand/do Public Health/Title V work 	Mutually Reinforcing Activities
Continuous Communication	<ul style="list-style-type: none"> ● Weekly bulletin ● Regular Steering Committee meetings ● Annual Summit 	Continuous Communication
Backbone Support Organization	<ul style="list-style-type: none"> ● PAVE, Washington’s Family to Family ● State Title V CYSHCN Program’s Family Engagement Coordinator 	Backbone Support Organization

HEALTH EQUITY

WSLI membership includes the state’s Family-to-Family Health Information Center and the Parent to Parent groups located around the state, as well as several other family led, community based organizations providing family support and leadership development around the state. By supporting community based organizations, WSLI seeks to leverage those community relationships in order to have an increased reach, with added focus into geographically and culturally diverse and underserved communities. As the Title V program works to promote health equity for families in Washington State, working with community based organizations who serve diverse families utilizing cultural brokering strategies allows us to engage with families of CYSHCN that our program may not typically have reached. WSLI partners with several organizations who specialize in supporting culturally and linguistically diverse families, who employ staff with multilingual and multicultural expertise, such as Open Doors for Multicultural Families and relationships with Vietnamese and Somali health groups. 14 of our Parent to Parent programs employ bilingual Latino staff who provide Spanish-speaking support to families across the state.



EVIDENCE OF EFFECTIVENESS

The coalition is in the process of defining our shared data metrics through the RBA framework. Population and performance-based metrics will be decided to evaluate effectiveness of the coalition as a model along with reach and quality of trainings, events, and outreach offered throughout the state. Qualitative data is collected regularly from steering committee members to help guide the logistics of future meetings as well as the overall direction of the coalition's aims and objectives. Surveys have also been collected to assess partnerships and connections between WSLI members, creating a baseline metric. None of these tools have been published at this time.

Section 2: Implementation Guidance

STAKEHOLDER EMPOWERMENT & COLLABORATION

WSLI is built on strong, collaborative partnerships between professionals, nonprofits, and family leaders. WSLI has a strong Steering Committee made up of various partners, and always open to new members. PAVE, the State Family to Family Health Information Center, serves as the main backbone support agency and longtime active member of WSLI. The F2F Director at PAVE regularly attends meetings and forms connections to help bring new members along. Other longtime members who serve on the Steering Committee include the Statewide and local Parent to Parent Coordinators, Washington State Fathers Network, the University of Washington's Medical Home Partnership Project, Seattle Children's Hospital, and the Northwest Autism Center. Other organizations are also involved in WSLI now, though it is impossible to give a complete list as membership continues to grow, here are a few:

- Hope Central
- Kindering Center
- University of Washington's LEND Program
- Washington State Community Connectors
- Within Reach, Washington State's designated Help Me Grow Affiliate and Learn the Signs, Act Early Ambassador
- Washington Hands and Voices
- Developmental Disabilities Council
- And many more!

Networking with potential members and building meaningful relationships between members has been vital to sustaining and growing membership over the years. Many of the founding partners of the coalition still participate in regular Steering Committee meetings and are some of the biggest supporters of WSLI. As a coalition, WSLI members have collective ownership over the direction of the



group's efforts. The mission, vision, and values statements were collectively created and are regularly reviewed and revised by steering committee members. After-meeting plus delta surveys serve as a CQI tool to assess meeting efficiency and direction for future meetings and endeavors. The FEC within the State Title V CYSHCN Program coordinates and convenes meetings, but the group as a whole directs the meeting focus. This shared ownership validates all perspectives and helps keep activities and discussions meaningful to those involved.

REPLICATION

The WSLI coalition was created as a replication of an Innovation Station Best Practice and has evolved to become a promising practice of its own. We would invite collaboration with others to promote the elevation of family voice and development of family leadership.

INTERNAL CAPACITY

WSLI Coalition Coordinator and Project Staff (0.8 FTE):

- The Family Engagement Coordinator (FEC) within the State Title V CYSHCN Program played a vital role in implementing WSLI as a coalition alongside key partners who were contracted with the CYSHCN Program. The FEC dedicates .3 FTE to maintaining a steering committee of interested and key partners, creating a weekly bulletin to connect, facilitating and coordinating regular steering committee meetings, sub-committee meetings, and the annual in-person Summit. Preferred candidates for this position are skilled in facilitating discussions, big-picture oriented, and excellent networkers.
- PAVE, the state's Title V funded Family to Family, serves as the backbone support agency for WSLI. The F2F Director at PAVE is actively involved in the coalition's work and PAVE supports a .5 FTE Administrative Support to WSLI. This position assists in coordinating, planning, and facilitating the annual Summit, as well as maintains the coalition website information and list of events. PAVE is uniquely qualified to serve in this role as the state's Family to Family Health Information Center and Family Voices affiliate. PAVE has a direct tie to and understanding of Title V work, while also possessing the ability to partner with other family led organizations and family leaders to offer technical assistance and support.

Support Structures:

- Washington State Department of Health, Office of Family and Community Health Improvement supports a Family Engagement Coordinator within the CYSHCN program at 1 FTE, who covers the .3 FTE to lead and convene WSLI.
- CYSHCN team who provide in-kind support and connections for various partners and contractors connected to WSLI and within the State Title V Program.



- Washington State Title V MCH Director who supports strong family and consumer partnership across MCH domains including, but not limited to, the CYSHCN Program.
- PAVE, the State Family to Family entity, who contracts and works closely with the CYSHCN Program and FEC to support the coalition as a backbone support agency and one of the original founding members.

PRACTICE TIMELINE

Phase: Planning/Pre-Implementation

Activity Description	Time Needed	Responsible Party
Application to Innovation Station to replicate a Best Practice	July-September 2015 8 hours	CYSHCN Supervisor
Planning for site visit to NJ	October 2015- January 2016 5 hours a month (20 total)	CYSHCN FEC
Site visit to NJ SPAN	February 2016 3 days travel	CYSHCN FEC & Partners
Kick off Statewide meeting prep	February - April 2016 5 hours a month (10 total)	CYSHCN FEC & Steering Committee

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Convening Workgroups	May 2016 – January 2017 8 hours a month	CYSHCN FEC



CQI around Workgroup outcomes	May 2016 – January 2017 2 hours a month	CYSHCN FEC
Technical Assistance with MCH WDC	September 2017 – February 2019 3 hours a month	CYSHCN FEC & MCH WDC
Implementation Assessment (part of a larger Family Engagement Business Analysis)	October – November 2017 8 hours a month	CYSHCN FEC & MCH WDC

Phase: Sustainability

Activity Description	Time Needed	Responsible Party
Develop Contract with PAVE	January 2018 3 hours	CYSHCN FEC & F2FHIC
Regular meetings: Steering Committee, Workgroups, Annual Summit	Continual 3-4 hours a month	CYSHCN FEC
Weekly WSLI Bulletin	Continual 8 hours a month	CYSHCN FEC
Continued Title V Trainings and Technical Assistance	Continual 2-3 hours a month (varies)	CYSHCN Program & F2FHIC
Partner Trainings and Technical Assistance	Continual 1 ½ -3 hours a month (varies)	Partners



WSLI Website Maintenance	Continual 1 ½ - 5 hours a month (varies)	F2FHIC
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PRACTICE COST

The Title V FEC and PAVE contract are funded by the Title V Maternal and Child Health Block Grant Program through the Washington State Department of Health, Children and Youth with Special Health Care Needs Program.

Budget			
Activity/Item	Brief Description	Quantity	Total
FTE	DOH Title V Family Engagement Coordinator staff time	0.3	In-kind
FTE	PAVE (F2FHIC) staff time	0.5	\$20,000
Website	Start up and maintenance of website, including regular updating of events, trainings, and information. Staff Time for web maintenance	N/A.	\$8,000 (one-time, start-up) \$200- \$400 yearly (varies)
Annual In-Person Meeting	Supplies, food, location, honorarium, travel stipends, rooms	Varies	\$8,000
Total Amount:			\$36,000 (startup cost) \$28,300 (annually)



LESSONS LEARNED

Assets of this Practice:

- A coalition model allows for shared partnership and leadership which resulted in increased collaboration and resource sharing among the various nonprofits and diverse stakeholders within Washington.
- WSLI serves as a networking hub for WSLI members to be able to connect with others doing the same or similar work and build robust partnerships.
- WSLI's website and weekly bulletin increase sharing capacity for trainings and other opportunities to connect with and serve a broader audience of families on a wider range of topics.
- The increase in trained family leaders in the state has built a cadre of advocates who are trained and able to share their stories.
- Results Based Accountability has been an easy to understand framework that has engaged family partners in outcome-based program planning and evaluation.

Challenges of this Practice:

- Changing a system takes time and does not always work the same way as changing direct services. Different state agencies have different roles and expectations, often leading to confusion. There is a challenge around educating the public, including some who have contracted with the Department of Health, to understand the role of Public Health in systems level change.
- Families are often used to advocating for direct services. As Title V moves to a focus on systems change, there needs to be mechanisms in place to help families and family led organizations understand systems integration and how it differs from direct services.

Overcoming the Challenges:

- The role of Public Health is unique and intentional education about that role and the fundamental foci is essential to working effectively with partners.
- Educational resources about Maternal and Child Health work are shared through the weekly bulletin and website for partners. Trainings are also provided at times.
- Engaging, interactive trainings, such as using "gamified" formats to teach MCH Leadership competencies have been utilized to increase understanding and connect to adult learning styles.
- Maintaining momentum and being willing to table structural activities in favor of activities to keep people engaged and then readdress structure at a later time with committed partners.

Lessons Learned:

- It is important to maintain constant momentum so that partners can feel and see that there is progress being made toward specific goals. It can be easy at times to get caught up on small details. Facilitation skills and relationship building are necessary to ensure active stakeholder



engagement, while honoring every member's voice. Solicitation for feedback can come through other methods, such as email inquiries, key informant interviews, and meeting evaluations to avoid stalling the group's focus and energy.

- All partners should be valued. There must be an active effort to recognize and elevate the work of all partners in the coalition, not just those that can provide the most time or energy to the cause. Small nonprofits and organizations that are based in rural or underserved communities can bring new perspectives, just as larger, better funded, or better connected organizations. It is important to value all participants and push for diverse and representative participation.
- While structure and scope are important, allowing dedicated time for organic exploration of shared goals, relationship building and collaboration between partners, and training to develop shared technical knowledge of Title V and public health provides an upfront time investment to address key implementation drivers.

NEXT STEPS

The WSLI coalition launched in 2016 after a year of planning. It was initially a replication project of an Innovation Station Best Practice that was adapted to meet the needs of Washington State, which is much larger in size than the original practice had covered. The coalition is still thriving. The weekly bulletin went out to 3,000 people as of May 1, 2021 and that number continues to grow steadily every week. The Steering Committee and PAVE, the backbone support, are working with the FEC to update the mission, vision, and values statements while also defining shorter term goals that can focus the group over the next two years.

The Title V CYSHCN Program is exploring evaluation methods that can be used alongside RBA. A full evaluation plan will be created that can monitor progress and impact on population and performance measures as determined by the Steering Committee and/or Evaluation sub-committee.

WSLI is interested in opportunities to help aid in replication of the coalition model for use in increasing family and consumer partnership.

RESOURCES PROVIDED

- Lucile Packard Foundation for Children's Health Standards for Systems of Care for Children and Youth with Special Health Care Needs, Version 2.0. AMCHP, the National Academy for State Health Policy, and the Lucile Packard Foundation for Children's Health released an updated version of the [Standards for Systems of Care for CYSHCN](#) in 2017. These standards are built around providing comprehensive and coordinated care for all CYSHCN within a Medical Home model.



- Results-Based Accountability Implementation Guide. RBA is also called Outcome-Based Accountability. This [guide](#) provides an overview of RBA, portrayed as answers to questions asked.
- [Stanford Social Innovation Review \(2011\) Collective Impact](#). Article examines coalition efforts and highlights five key factors that correlate to success.
- [National Implementation Research Network at the University of North Carolina at Chapel Hill](#). NIRN partners with organizations to ground practices in implementation science in order to improve outcomes.
- [Washington Statewide Leadership Initiative \(WSLI\) Coalition Website](#)
- 2017 DOH Internal Business Analysis. This is not currently linked anywhere public, but we are willing to share. If you are interested, please email Nikki.dyer@doh.wa.gov.

APPENDIX

- N/A.

