



Children & Youth with Special Health Care Needs

www.doh.wa.gov/cyshcn

000000

COMMUNICATION NETWORK MEETING

October 10, 2024

CYSHCN Communication Network Purpose:

Provide for exchange of information among those programs and entities that serve children with special health care needs and their families and facilitate an opportunity to learn more about statewide policies, programs and issues critical to this unique population.

Contents

COMMUNICATION NETWORK MEETING	1
Attendees.....	4
Children and Youth with Special Health Care Needs (CYSHCN) Program Update.....	7
General Updates.....	7
Child Health Intake Form (CHIF) Database.....	7
CYSHCN Communication & Early Childhood	7
Washington Statewide Leadership Initiative (WSLI) and DOH Family Engagement.....	7
CYSHCN Program Nutrition Updates	8
CYSHCN Behavioral and Adolescent Health	8
Essentials for Childhood (EFC).....	8
Universal Developmental Screening (UDS).....	8
MCH LHJ Contracts Updates	8
CYSHCN Communication Network Agenda	9
Time	9
Topic.....	9
Guest Presentations	9
Family Voice: Centering Joy in the Neurodivergent Community	Error! Bookmark not defined.
Domestic Violence, Neglect, and Child Protective Services (CPS)	Error! Bookmark not defined.
CSHCN Coordinator Updates by County	21
Grays Harbor County Public Health	21
Grant County Health District	21
Island County Public Health	21

Jefferson County Public Health.....	21
Pacific County Public Health and Human Services	21
San Juan County.....	21
Spokane Regional Health District.....	21
Thurston County Public Health and Social Services.....	21
Yakima County- Children’s Village	22
Neurodevelopmental Center (NDC) Updates	22
Peace Health Children’s Therapy - Whatcom County	22
Children’s Therapy Skagit Valley Hospital.....	22
Children’s Therapy Valley Medical Center.....	Error! Bookmark not defined.
Kinding.....	22
HOLLY RIDGE	22
Children’s Therapy Center.....	23
May Bridge Children’s Therapy Services.....	23
Health Plan Updates	23
Wellpoint (Amerigroup Washington).....	23
Community Health Plan of Washington (CHPW).....	23
Coordinated Care.....	23
Molina Healthcare of Washington	23
UnitedHealthcare.....	23
Partner Updates	24
Washington State Parent to Parent Network.....	24
Washington State Medical Home Partnerships Project for CYSHCN	24
University of Washington CSHCN Nutrition Project at CHDD	24
Washington State Fathers Network (WSFN)	24
Family to Family Health Information Center (F2FHIC).....	24
Open Doors for Multicultural Families.....	24
Washington Autism Alliance & Advocacy (WAAA)	24
Office of Superintendent of Public Instruction (OSPI)	24
Seattle Children’s Hospital.....	25
Lifespan Respite Washington (LRW)	25
WithinReach.....	25
State Updates.....	25
Department of Children, Youth, and Families.....	25
Early Support for Infants and Toddlers (DCYF-ESIT).....	25

DSHS, Fostering Well-Being (FWB) 25

DSHS, Developmental Disabilities Administration (DDA), Waiver Unit 25

DSHS / DDA, Medically Intensive Children’s Program 25

DCYF, Family & Community Supports, Division of Partnership, Prevention and Services 26

DSHS / ALTA, Kinship Care and Lifespan Respite 26

DOH Screening and Genetics Unit..... 26

Health Care Authority 26

Attachments 26

Next Meeting 26

Attendees

Attendee	Phone	Email Address
Abigail Osborne-Elmer, Wellpoint		abigail.osborne-elmer@amerigroup.com
Ama Owusu-Madrigal, Epi, DOH		ama.owusu-madrigal@doh.wa.gov
Amanda McCleskey, DSHS/Fostering Well-Being		
Amanda Simon, CYSHCN Process Improvement Specialist, DOH		amanda.simon@doh.wa.gov
Analiese Brock		
Andrea Weeks		
Arzu Forough, WAA		
Autumn Wade, DSHS, Foster Well-Being Program		autumn.wade@dshs.wa.gov
Ayan Elmi, WMSL		
Bonnie Peterson, CYSHCN Coordinator, Thurston County		bonnie.peterson@co.thurston.wa.us
Brianne Cline, Developmental Disabilities Coordinator, Pacific County		bcline@co.pacific.wa.us
Cassie Mitson, United Health Care		cassie_mitson@uhc.com
Charla Morrow, RN, Wellpoint MCO		charla.morrow@wellpoint.com
Crisha Warnstaff, Okanogan County Public Nurse, Okanogan County		lwarnstaff@co.okanogan.wa.us
Dennis Trudeau, DDA Washington State		dennis.trudeau@dshs.wa.gov
Derek Steele, Amerigroup		derek.steele@anthem.com
Diana Castillo, WithinReach WA		dianac@withinreachwa.org
E Renae Antalan, DCYF, ESIT		erenae.antalan@dcyf.wa.gov
Elizabeth Custis, RN, Mason County Public Health, CSHCN	360-427-9670 x 407	elizac@co.mason.wa.us
Elizabeth Stringer, CYSHCN Coordinator, Garfield County Public Health		estringer@garfieldcountywa.gov
Emily Matinez, CYSHCN Care Coordinator, Tacoma-Pierce Co Health Dept		EMartinez@tpchd.org
Estasia, Columbia County Public Health		
Faire Holliday, MCHBG, DOH		faire.holliday@doh.wa.gov
Gabriella Connell, RN, Skamania County		
Gayle Reid, Cowlitz Co Health Dept		reidg@co.cowlitz.wa.us
Heather Eliason, Seattle & King County		
Iana Bezman, WA HCA		iana.bezman@hca.wa.gov
Jan Schmalenberger, CYSHCN Coordinator, Clark Co Public Health		Jan.Schmalenberger@clark.wa.gov
Janet Wyatt, Kitsap Public Health		
Jenna Hahn		
Jill McCormick, PAVE	253-565-2266	jmccormick@wapave.org

Attendee	Phone	Email Address
Jo Ashley, APNS-PCH		josephine.ashley@kingcounty.gov
Jodi Van Vleet		
Jordan Labayen, Public Health Nurse, Strengthening Families, TPCHD		jlabayen@tpchd.org
Kaelyn Carlson		
Kasey Thomas, Case Manager WLP		
Kathryn Defiloppo		
Katie Ladner		
Kelly Anderson, Molina, MCO		kelly.anderson@molinahealthcare.com
Khimberly Schoenacker, CYSHCN Nutrition Consultant, DOH		Khimberly.Schoenacker@DOH.WA.GOV
Kimberly McLaury		
Kindra Ahmann, CYSHCN Coordinator, Tacoma-Pierce Co Health Dept		KAhmann@tpchd.org
Kristen Rezabek, San Juan County	360-370-7518	kristenr@sanjuanco.com
Kristin Lester, RN, Spokane Regional Health District		klester@srhd.org
Kristy Scheidt, RN, Joya Child & Family Development		Kristy.schedit@joya.org
Krystal Ceron, Walla Walla County Region 1, DSHS/AL TSA/Fostering Well-Being		
Kyser Corcoran, DSHS/AL TSA/Fostering Well-Being		
Linda Ramirez, CYSHCN WA Dept of Health		Linda.Ramirez@doh.wa.gov
Malvina "Annie" Goodwin, Benton Franklin Health Department		
Mari Mazon, UW IHDD Nutrition		
Maria Vargas, Grant Health District		
Mary Jo Schatz, Tacoma-Pierce County Health Department		mschatz@tpchd.org
Matthew Rickmon, Washington State Fathers Network		
Megan Boardman		
Meghan Hopkin, DSHS DDA		
Melia, Kitsap County Parent Coalition		
Melissa Petit, HCA		
Michaela Phillips, DOH		michaela.phillips@doh.wa.gov
Michelle O'Dell		
Molly Corvino, NETCHD		mcorvino@netchd.org
Monica Burke, DOH CYSHCN Director	360-236-3504	monica.burke@doh.wa.gov
Natalie Todd, CYSHCN Coordinator, NETCHD		ntodd@netchd.org
Nicole Christiansen		
Nikki Dyer, Family Engagement Specialist, DOH CYSHCN		nikki.dyer@doh.wa.gov

Attendee	Phone	Email Address
Nora Downs, DOH/ONS		
Rachel Parsons, Suquamish Tribe		rparsons@suquamish.nsn.us
Renee Bailey		
Sabrina Golden, OCPHD		
Sara Brugger, Clark Co Public Health		sara.brugger@clark.wa.gov
Sarah Bunny, Joya Child & Family Development		sarah.bunney@joya.org
Shana Van Horn, Providence Children's Center		
Sherry Bennatts, Coordinated Care	253-442-1543	sbennatts@coordinatedcarehealth.com
Stefani Joesten, Grays Harbor County Public Health		
Stephanie Hokanson, SPARC		sjoesten@co.grays-harbor.wa.us
Stephanie Larsen, PHN, MCH		larsens@cowlitzwa.gov
Stephanie White, NETCHD		
Susan Adelman, UW LEND		adelms@uw.edu
Suzie Tallar, Coordinated Care Case Manager		
Tiffany Hooper, DOH		
Tracie Hoppis, Children's Village/P2P	509-574-3263	tracie.hoppis@multicare.org
Trish Squires		
Whitney Wheelock, CYSHCN Coordinator, Kittitas County Public Health		whitney.wheelock@co.kittitas.wa.us
Will Moncrease, DCYF/ESIT		will.moncrease@dcyf.wa.gov
Zahra Roach, Executive Director, Children Developmental Center		zahra@childrensdc.org

Guests:	
Brynn Stopczynski, DOH	Brynn.Stopczynski@doh.wa.gov
Amy Bertrand, DOH	Amy.Bertrand@doh.wa.gov
Kristina Somday, DOH	Kristina.Somday@doh.wa.gov
Renee Bailey, DOH	Renee.Bailey@doh.wa.gov
Mary Dussol, DOH	Mary.Dussol@doh.wa.gov
Shawnda Hicks, PAVE	shick@wapave.org

Children and Youth with Special Health Care Needs (CYSHCN) Program Update

www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/ChildrenwithSpecialHealthCareNeeds.aspx

General Updates

BluePrint

The DOH CYSHCN Team and family and community partners are currently working with the National Center for Services for CYSHCN on developing Blueprint Implementation Projects.

Our focus is on strengthening family-centered, interdisciplinary care coordination including a shared plan of care and a peer support component. We will be implementing projects over the next year to support this goal.

Priority Strategies:

- Care Coordination System Mapping
- Providing input to HCA as they develop state plan amendment for Ace Kids Act Health Homes
- Looking at models of integrated peer support for CYSHCN

Child Health Intake Form (CHIF) Database

- CHIF Office Hours- 4th Wednesday of the month. Please email amanda.simon@doh.wa.gov if you need the meeting invite.
- Be on the lookout for CHIF orientation and guidance materials!
- Please continue to submit all CHIF data via MFT.
- If you run into any issues with the MFT tickets need to be submitted via [survey monkey](#) , if you can not access the survey monkey, please email amanda.simon@doh.wa.gov.

For more information, contact Amanda Simon at Amanda.Simon@doh.wa.gov

CYSHCN Communication & Early Childhood

- New quarterly GovDelivery CYSHCN Communication Network newsletter! Sign up here: [Washington State Department of Health \(govdelivery.com\)](http://WashingtonStateDepartmentofHealth.govdelivery.com)

For more information, contact Linda Ramirez at Linda.Ramirez@doh.wa.gov

Washington Statewide Leadership Initiative (WSLI) and DOH Family Engagement

- Supported the CYSHCN Family Advisory Council meeting in September focused on the MCH Needs Assessment results and prioritization process.
- Supported facilitated discussions with the YAC's Youth with Special Health Care Needs subcommittee regarding the MCH Needs Assessment.
- Promoting FESAT use within DOH programs through a FESAT Community of Practice.
- Newly elected as a Family Representative to the AMCHP Board of Directors.

For more WSLI or DOH Family Engagement information, contact Nikki Dyer at 360-236-3536 or nikki.dyer@doh.wa.gov.

CYSHCN Program Nutrition Updates

- Coming soon! Eating disorder guide created in partnership with Youth Advisory Council (YAC) nutrition subcommittee, check [Teen Health Hub WA | Washington State Department of Health](#) in 1-2 months
- [Empowering Culinary Exploration: Tips for Teaching Cooking Skills to Youth with Disabilities](#) is online and a quarterly meeting for educators who are teaching cooking classes to youth with IDD is starting soon, please email if interested: Khimberly.schoenacker@doh.wa.gov
- The T1D workgroup is still going strong. All up-to-date flyers are listed under resources/partners/provider/T1D workgroup at www.doh.wa.gov/CYSHCN
- T1D Teen Connect is being extended another year and we are expanding to all US states. The QR code remains the same.
- Help us build the T1D Family Support program, please share the flyer among your T1D population: [Washington Type 1 Diabetes Family Support](#)

For more information, please contact Khimberly Schoenacker at 360-236-3573 or khimberly.schoenacker@doh.wa.gov.

CYSHCN Behavioral and Adolescent Health

No update at this time.

Essentials for Childhood (EFC)

No update at this time.

For more information, contact or see www.doh.wa.gov/efc.

Universal Developmental Screening (UDS)

No update at this time

For more information, contact Marilyn Dold at Marilyn.dold@doh.wa.gov.

MCH LHJ Contracts Updates

No update at this time

For more information, please contact Mary Myhre at Mary.Myhre@doh.wa.gov

CYSHCN Communication Network Agenda

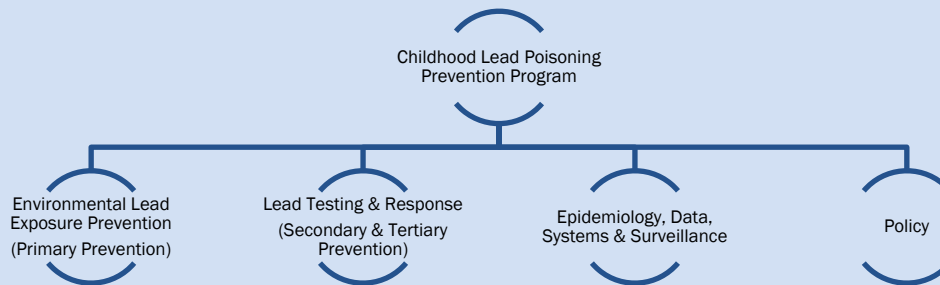
Time	Topic	Presenter
9:00-9:30	Welcome, Agenda, Program Updates	Linda Ramirez
9:30-10:10	Childhood Lead Poisoning Prevention	Kristina Somday, Amy Bertrand, Renee Bailey, and Mary Dussol, DOH
10:10-10:50	Family Engagement in Systems Assessment Tool (FESAT)	Shawnda Hicks, PAVE
10:50-11:00	Break	
11:00-12:00	Maternal and Child Health 5-year Needs Assessment Process & Prioritization Activity	Brynn Stopczynski, DOH

Guest Presentations

Childhood Lead Poisoning Prevention

Kristina Somday, Amy Bertrand, Renee Bailey, and Mary Dussol, DOH

DOH Program Components



Who We Are and What We Do

- The Child Lead Prevention and Response Team has three focus areas:
- Blood Lead Testing promotion
 - Outreach and education to health care providers
 - Outreach and support for families
- Elevated Blood Lead Case investigation and response
 - Administering the statewide database (WDRS)
 - Technical Assistance to support Local Health in their response
 - Offering backup case management assistance when requested
- Partnership

- Convening the statewide Lead Advisory Committee
- LHJ Lead Prevention Contact List
- Connecting individuals and agencies in our lead prevention efforts

Effects of Lead:

- Lead is a naturally occurring toxic metal and is still widely used in many products and industries. This has resulted in broad environmental contamination.
- Lead in the body:
 - Neurotoxin
 - Affects brain, kidneys, and heart
 - Stored in teeth and bones
 - Long-term, often irreversible, health impacts
- Health impacts are greater for children:
 - Absorb more than adults
 - More hand-to-mouth behavior
 - Impacted by nutritional status – iron, calcium, vit c

Children are the Most Vulnerable

- Developing children are much more sensitive to the adverse effects of lead.
- Especially harmful to developing brains and nervous systems.
- Children absorb more of the lead they are exposed to.
- Young children exhibit more hand-to-mouth behavior, increasing their exposure and intake.
- Usually children don't show signs of lead exposure, this is why blood lead testing is important.
 - Example lead exposure consequences: Brain Affects IQ at low levels, potential hearing loss, attention and behavioral issues.

Potential Sources of Lead Exposure

- Paint and paint dust from prior to 1978
- Dirt/Soil
 - Historical pesticide use
 - Historical smelter industry
- Water sources
- Recalled toys and costume jewelry
- Job and hobby hazards (“take home lead”)
 - Leaded glass
 - Construction
 - Ammunition and fishing hobbies/jobs

Cultural products

- Pottery/ceramic glaze
- Spices and candy
- Traditional remedies
- Aluminum cookware

Lead Exposure Risk Mapping

- The Washington Tracking Network (WTN) Lead Risk Indicator is calculated utilizing data on age of homes and poverty within census tracts.
 - Shows all the different ways that you can be exposed to lead due to where you are living across the state of Washington.

Testing for Lead Exposure

- There is a common misconception that lead exposure is not a risk anymore in the United States and specifically here in Washington. While the rates of lead poisoning have been dramatically reduced over the years, there are still many sources of exposure that impact our children's health. So, it is important to promote education on uncommon lead exposures, so exposure sources and increase our testing rates.

Who Should Get Tested?

- Federal regulations require that **all children enrolled in Medicaid (Apple Health)** receive a blood lead test at 12 months and 24 months, or at 72 months of age if no record of a previous test exists – this is required even if they don't have other risk factors!
- Children not covered by Medicaid should have a blood lead test at 12 and 24 months old if screening identifies 1 or more risk factors for lead exposure using the [clinical algorithm](#).
- All newly arrived refugee and immigrant children 16 years and younger.
- People who are pregnant or lactating and may have been exposed to lead.

Testing Methods

Two methods for blood lead testing:

1. Venous (does *not* need confirmatory test)
2. Capillary (*needs confirmatory test* conducted within 12 weeks of initial blood lead test)

Blood Lead Test Result Reporting

- Required under WA Blood Lead Reporting Rules **WAC 246-101**.
- All blood lead level test results must be reported to DOH (elevated, non-elevated, adult, child).
- Elevated results must be reported within two business days, non-elevated monthly.

Response to Elevated Blood Lead

- Each county has jurisdiction over the EBLL response for its residents.
- Local health response may include telephone contact, a home assessment, and other services.
- DOH provides technical assistance and can conduct response to EBLL cases at local health request.
- Goals of response:
 - Identify likely source(s) of lead exposure
 - Provide education on reducing exposure
 - Encourage follow-up blood lead testing

- Connect families to appropriate resources

Developmental Considerations

- Children exposed to lead need extra support to grow and thrive.
- Multi-faceted approach:
 - Reduction or removal of lead in the immediate environment.
 - Parent education about lead-safe cleaning and harm reduction.
 - Nutritious diet rich in calcium, iron, vitamin C.
 - Early enrichment.
 - Education and collaboration with those who work with young children.
 - Referrals to services, including developmental screening.

Current and Future Work to Enhance Case Management

- Foundational Public Health Services Lead Prevention Core Team
 - Local Health and DOH co-leads and members
 - Created Best Practice Manual (in final revision stage)
- Enhancing Case Investigation Database to:
 - Better identify sources of exposure
 - Follow cases until blood lead levels decrease
 - Track linkages to services and resources

MCO and Public Health Collaboration

Enhancing services to families of children with elevated blood lead levels

- Elevated blood lead case data match
- 2024: New HCA contract requirements for lead prevention include “referral” to public health.
- MCO Collaboration Request Form process – pilot for 2024
 - Possibilities:
 - o Share information
 - o Coordinate messaging to families to avoid confusion
 - o Coordinate messaging to health care providers

What Can You Do?

- **Encourage testing** in alignment with federal Medicaid requirements and testing algorithm.
- Help us raise awareness, particularly among health care providers, that **children in WA are still being exposed to lead.**
- Contact us to **learn more about childhood lead poisoning prevention** efforts in your community.
- **Visit our website** for general information on lead and prevention suggestions:
<https://doh.wa.gov/community-and-environment/contaminants/lead>

Lead Publications:

Questions and Answers:

Q: Do providers get notified by the Washington Medical Provider Association already?

A: Kind of... still working on being connection but not very systematic the way it's being done. There are some providers who know about it and are on board and other who are less so.

Q: Are there lead and baby food and/or formula?

A: Unsure, but Lead team always share whatever resources that they have and when they learn about recalls, they share that information.

Q: Lead in cinnamon?

A: There has been recall on cinnamon

Q: Clinics doing capillary testing with false positives and increased elevation. Is there communication to the clinics on the importance of venous draws and follow-up confirmation draws?

A: Yes, that is part of our work and work with the Pediatric Environmental Health Specialty Unit. There are lot of capillary tests that never wind up having a confirmatory test.

Q: How do we share this information to immigrant families?

A: With our resources and on our Department of Health webpage there are materials that people can order. We have lead test card and we have lead information in 17 languages.

Family Engagement in Systems Assessment Tool (FESAT)

Shawnda Hicks, PAVE

Objectives

Learners will be able to:

- Explain why we engage families in our improvement work
- Identify and describe the difference between individual and systems-level family engagement activities
- Explain the uses of the Family Engagement in Systems Tools to plan, assess, and improve family engagement in systems over time

About Family Voices

Family Voices is a family-led organization that transforms systems of care to better work for all children and youth, especially those with special health care needs and disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes.

Learn more at familyvoices.org.

Why Engage Families?

Meaningful partnership at the systems level integrates the importance and value of basing policies, programs, and services on the lived experiences of families who navigate fragmented systems that creates barriers in their everyday lives.

Families bring context to data and solutions that bring the fragments together.

Families are deeply affected by issues such as care fragmentation that results from:

- lack of communication
- lack of education
- ineffective and outdated health care policies

Evidence indicates that family partnership at the individual level improves care coordination and health outcomes.

Family engagement can reduce system fragmentation, remove barriers to health care and improve the quality of health care.

Levels of Family Engagement

Individual Family Engagement

- My child's doctor and I discuss the results of my child's developmental screening.
- A maternal and infant community health worker provided smoking cessation counseling to a pregnant woman.

Systems-Level Engagement

Systems-Level Family Engagement

- A Title V program engaged families as part of a family advisory council to co-design an improved referral process to early intervention services.
- A hospital engaged families in the co-design of a smoking cessation program to ensure women who are planning to have a baby or who are pregnant have access to culturally appropriate supports to stop smoking and create smoke free homes.

Framework for Family Engagement

Commitment

Commitment means an organization always engages families they serve in decision-making groups that are working to improve or create the policies, programs, and services that children, youth, and families receive.

Have a Policy:

Have a family engagement policy that requires family engagement in systems-level initiative.

- This sets a standard that families need to have role in creating or improving policies.
- Ensures policies are family-centered and equitable.

Leadership and Compensation:

Family Engagement champions

- Have one or more staff members lead the way for those who may not understand the value of family partnership.
- Compensate family partners
- Recognizes the value of families' time, experience, & expertise.
- Ensures equity, as many families cannot take time away from work and family.

Transparency

Transparency occurs when an organization documents and communicates how it identifies issues families experience and provides the information and supports families and staff need to partner, participate, and contribute to their maximum potential.

Identify the Issues:

Use internal data or partner with family-led or community-based organizations to learn what they are hearing from families.

- Co-create needs assessments, surveys, other feedback loops.
- Reach families directly
- Uses data from a variety of sources.

Provide Information and Support:

Describe the opportunity

- Moves families “beyond the checkbox.”
- Provide mentors
- To help families & staff prepare for meetings.
- To help families learn to use their experiences to improve systems of care for all families.
- Share meeting materials in advance.
- Jargon free

Representation

Representation occurs when the families who are engaged in the initiative reflect the diversity of the community served by the organization.

Equal Representation:

Engaged families reflect the diversity of those served by a specific systems-level initiative.

- Use internal or external data to understand the demographics of families served.
- Connect with a family-led or community-based organization that supports families who are diverse.

Provide Support:

Provide mentoring and skill-building opportunities for both families and staff. Examples:

- Workshops about parent-professional partnerships.
- Implicit bias training so all participants are aware of assumptions they may make.

Impact

Impact describes how and where the organization used families’ input and ideas to improve existing policies and practices or to create new ones.

Listen:

Families know what works and what doesn’t work about systems of care.

- Listen to their lived experiences.
- Work together to identify areas for improvement.
- Work together to identify solutions.

Identify what has changed:

Staff and families can identify what the organization is doing differently because families were engaged in the initiative.

- Document families' contributions to the work.
- If needed, work together to create an action plan to improve family engagement in systems-level initiatives.

Three Uses of the FESAT

Use 1: Plan for Family Engagement

Child- and family-serving organizations can use the Checklist in the Family Engagement in Systems (FES) Toolkit to establish family engagement processes.

- Identify supports already in place to ensure meaningful family engagement.
- Explore strategies and resources for additional ways to encourage and support family engagement.

Checklist to Plan a Family Engagement Initiative

Use 2: Assess Family Engagement

Families and staff can use the FESAT to learn whether families have the information and supports they need to participate, partner, and contribute to decision-making groups.

- Compare perspectives on how family engagement is going.
- Identify what is working well.
- Identify areas for improvement.

Scoring the FESAT

- Staff and family participants score the tool
- They can do this individually
- More often, staff and families score the tool as separate groups
- Both groups meet to discuss differing perspectives
- They come to a consensus score for each item

REMEMBER

- Respond to the items based on the work they did together.
- Each person should score from own perspective/experience.
- Do not enter a score for Not Sure/Not Applicable responses.

Use 3: Improve Family Engagement

Families and staff can use the FESAT and FES Toolkit to track progress in family engagement efforts.

- Complete the FESAT and use the results as a baseline score.
- Identify an area for improvement and select a strategy from the FES Toolkit that can help.
- Complete the FESAT again at scheduled intervals and compare results to the baseline.
- The FESAT is a tool staff and families can score to improve family engagement in systems.
- You may want to begin by completing the FESAT for a specific initiative.

Using Results

- Identify domains of strength where families and staff felt supported in their role and had all the information and support they needed to partner and participate.

- Identify domains for improvement where your organization could better support families and staff in their partnership roles so they can make meaningful contributions to the initiative.
- Explore the FES Toolkit for strategies and resources to help the team improve family engagement in systems-level initiatives.
- Create an action plan for improvement (Strategy 4.4 in the FES Toolkit).

FES Toolkit

- The FES Toolkit includes one or more strategies that align with each item in the FESAT.
- Many strategies work across one or more domains.
- We update the FES Toolkit periodically with new strategies and resources.
- You can suggest strategies and resources that are not currently include in the Toolkit.
- We welcome suggestions for new strategies and resources to include.

Tools to Assess and Improve Family Engagement in Systems

The tools available at familyvoices.org/FESAT include:

- User’s Guide
- Family Engagement in Systems Assessment Tool (FESAT)
- FESAT Score Sheet
- Family Engagement in Systems Toolkit
 - The toolkit contains evidence-based strategies and resources that address each of the 20 items in the FESAT.

Learn more

1. Explore the four domains of the FESAT at familyvoices.org/FESAT/infographs.
2. Download the Family Engagement in Systems Assessment Tools at familyvoices.org/FESAT.
3. Request technical assistance to help your organization use the FESAT more effectively by emailing fesat@familyvoices.org.

Maternal and Child Health 5-Year Needs Assessment Process & Prioritization Activity

Brynn Stopczynski, DOH

2025 Needs Assessment Activities

• **Local Health Jurisdiction inputs:**

- Key informant interviews
- Emerging needs reporting
- NA reporting template

• **Key Informant interviews:** domain led

- **Facilitated discussions with partners**
- **Literature review & environmental scan**

• **Domain-Specific Evaluation and Needs Assessment Activities:**

- AYA Youth & Provider Surveys

- **Discovery Survey:**
 - 2,367 responses in 11 languages
 - Translated into English for analysis
- **Tribal Partner Needs Assessment:** Ongoing

Discovery Survey and Summarization:

Open Fall 2023 - Spring 2024 - Questions we asked:

- **What are the most important things families need to live their fullest lives?**
- **What are the biggest unmet needs of families in your community?**
 - Responses coded by MCHBG domain and topic area
 - Comments could be coded multiple times
 - **High-level “parent” codes:** basic needs, child health, perinatal
 - **More nuanced “child” codes:** housing, childcare, doula and birth-worker access

Responses by County

Highest responses:

- **Snohomish**
- **King**
- **Pierce**
- **Thurston**
- **Spokane**

Population: BIPOC

Needs and inequities that BIPOC families experience

Need	Inequity
Improved, culturally responsive and culturally matched care, especially maternal healthcare	Disparities in infant mortality among AI/AN, Black and NH/PI birthing people
Collaboration and community support for equity work	<ul style="list-style-type: none"> • Disparities in prenatal care • Access for Black and AI/AN mothers

“There is a significant bias against Black or African American or Indigenous low-income individuals giving birth. This has resulted in... needs of these individuals being unmet and to... trauma around the birthing process”-Community Health Worker

Population: Immigrant, Refugee, and Limited English

Systems-level issues and barriers to access care

Systems-level	Care-centered
Immigration reform and health coverage for people who are undocumented	Culturally matched care and services available in people’s native language
Access to education and job training regardless of immigration status	
Jobs that offer benefits, fair wages, and respect workers rights	

“Services in Spanish so that we can receive proper care without experiencing mistreatment or discomfort.”
Translation from a Spanish Discovery Survey Participant

Population: Sexually and Gender Diverse

Need for care and services for LGBTQIA+ people and families

Care	Services
Culturally-responsive and culturally-matched access to health care, especially mental health	Access to childcare, safe and welcoming community spaces and resources

“LGBTQIA+ mental health services... resources for parents, families and caregivers... healthy racial [an gender] identity development for children- these resources must come from the LGBTQIA+ community” Discovery Survey Participant

Population: Rural

Unique and specific challenges experienced by people in rural areas

Limited or no access
Health care, particularly specialists, dentists, mental health and maternal health providers
Parks and community recreational spaces
Higher education, childcare, and employment
Internet

“Transportation is a barrier for families who need to travel out of county for specialized health care visits. There is a lack of healthcare specialists in our area and families frequently need to travel 1-3 hours for these visits.”

--Rural LHJ Key Informant Interviewee

Population: Urban

Unique and specific challenges experienced by people in urban areas

High living cost concerns	Not feeling safe in their communities
Concerns about high living costs in King County	
Need for housing assistance and resources	
Under-resourced communities experience provider shortages and less access to services	Safety concerns limiting ability to use public and recreational spaces

“As a mother to two autistic children... South King County has a major lack of services for autistic people and their families: mental health providers who understand autism, OT and SLP providers, social support groups, and activities that can accommodate neurodiverse kids and teens.”

--Discovery Survey Participant

Population: Medicaid

Challenges experienced by people on Medicaid

Navigating complex systems
Few specialists, mental health providers and dentists accept Medicaid
Navigating Medicaid and social services can be complex
Eligibility cut off due to income

“I hear repeated stories about [people] having Medicaid, but not being able to find a dentist for treatment or needing procedures not covered by Medicaid and trying to pay out of pocket... [and] people who are just above Medicaid eligibility but can’t afford insurance.”

--Key Informant Interviewee

Population: Single Parents

Challenges and needs of single parents

Single mothers and fathers need support

Basic needs and improved financial stability

Employment and higher education opportunities

Flexible and affordable childcare to make it easier for parents to work or go to school

Include fatherhood needs in programming and services

“Approaches to fatherhood inclusion remain inconsistent. While many agencies and systems in Washington are focused on two-generation or whole-family approaches, they often primarily focus on single mother-child dyads or two-parent households and often miss non-cohabitating parents.”

--Key Informant Interviewee

Domain: Children and Youth with Special Health Care Needs

- Promotes **connected systems of care** for children and youth with diverse, special care needs from birth through transition to adulthood
- They may have or be at increased risk for **chronic medical conditions**
- Many areas of their life may be **impacted due to their complex medical needs**

Key Findings from Community and Partners | Domain: CYSHCN

- **Not enough support, respite care and personal care hours**
- **Shortage of** primary care, mental health, specialty and dental care providers that understand and accommodate CYSHCN
- Lack of affordable, accessible, and **CYSHCN-friendly caregivers**
- Need for financial assistance and **caregiver compensation**
- **Community building** and feeling of belonging
- Funding for **special education services** in school systems
- Access to **local resources for rural** CYSHCN families

19.3% of parents and other family members with CYSHCN in Washington left a job, took a leave of absence, or cut down on hours worked because of child’s health or health conditions compared to 18.1% nationwide

Comparing Washington to National Education Data

13.2% of CYSHCN students ages 5-21 served by the Individuals with Disabilities Education Act (IDEA) were identified with autism in Washington State, compared to 12.8% nationally

Suspensions and Expulsions for Students with Disabilities

- Students with disabilities have higher suspension and expulsion rates for discipline-related incidents than those without disabilities.
- Students of color with disabilities, especially Black students, experience more disparities.

Mental Health for Students with Disabilities

Students with disabilities have a greater risk of bullying, harassment, feelings of anxiety or depression, and thoughts of suicide than students without disabilities

Questions and Answers:

[Back to top](#)

Q: What can we be doing to better in Care Coordination? What can we learn from other states doing?

A: We are set up differently from other states in many ways

CSHCN Coordinator Updates by County

Gathered from counties and shared on a quarterly basis.

Grays Harbor County Public Health

Stefani Joesten, CYSHCN Coordinator

No updates at this time

Grant County Health District

Janetta Garza, CYSHCN Coordinator

No updates at this time

Island County Public Health

Loretta D. Bezold, RN, BSN, IBCLC, Public Health Nurse

No updates at this time

Jefferson County Public Health

Cynde Marx, CYSHCN Coordinator

No updates at this time

Pacific County Public Health and Human Services

Brianne Cline, CYSHCN Coordinator

<https://www.pacificcountyhealth.com/special-care>

San Juan County

Kristen Rezabek, MS, RDN, CD, CDE

No updates at this time

Spokane Regional Health District

Kristin Lester, Public Health Nurse, CYSHCN Coordinator

Coordinating quarterly Spokane Autism Collaborative, working to add local resources to HMG, planning a local Family Support Conference for families of children ages 3-14 with special needs.

<https://srhd.org/programs-and-services/children-youth-with-special-health-care-needs>

Thurston County Public Health and Social Services

Bonnie Peterson, CYSHCN Coordinator

<https://www.thurstoncountywa.gov/departments/public-health-and-social-services/community-wellness/parent-and-child-cyshcn>

Yakima County- Children's Village

Tracie Hoppis, Manager of Family Support Services, Yakima County CYSHCN Lead

Participating in WA DOH/CYSHCN Blueprint for Change project; Agency (Multicare) transition to new medical record; Continuing to host multi-disciplinary child and family staffing meetings, presented 5-year data trends to Children's Village leadership; Chair of Central Washington Interagency Transition (to adulthood) Network; hosting monthly Yakima County Care Coordinator's meeting- June presentation by Central Washington Help Me Grow.

<https://www.yakimachildredivillage.org/>

Neurodevelopmental Center (NDC) Updates

Peace Health Children's Therapy - Whatcom County

Kris Gaggero, Clinic Manager

No updates at this time

Children's Therapy Skagit Valley Hospital

Erin Kavi, Lead Therapist

www.skagitvalleyhospital.org

No updates at this time

Mary Bridge Children's Therapy Services

Kari Tanta, Rehab Manager

<https://www.marybridge.org/services/rehabilitation-physical-therapy/>

Please check out updates on our parent resource and workshops pages for the latest information.

Kindering

Kathy Fortner Director of Operations

www.kindering.org

No updates at this time

HOLLY RIDGE

Alicia Skelly, Infant Toddler Program Director

Holly Ridge is currently serving 500 children in Kitsap County, our largest enrollment to date!

Staff have been able to offer families the opportunity to participate in feeding groups run by an SLP and a Family Trainer. Currently 3 groups take place weekly.

In October Holly Ridge started a Pilot Program in collaboration with Kitsap Community Resources Called Growing Together which is an inclusive socialization opportunity for children and their caregivers. The groups meet for 2 hours Monday, Tuesday, Wednesday and Thursday.

A new PT started with us this month; we are slowly budling our staff.

Children's Therapy Center

Karen Smith Steadman Early Intervention Program Director and Jodi Van Vleet Center (3-18) Program Director

No updates at this time

May Bridge Children's Therapy Services

Kari Tanta, Rehab Manager

<https://www.marybridge.org/services/rehabilitation-physical-therapy/>

Please check out updates on our parent resource and workshops pages for the latest information.

Health Plan Updates

Wellpoint (Amerigroup Washington)

Derek Steele

[Home | Wellpoint Washington, Inc.](#)

[Coverage Area Includes: All Counties except Adams, Chelan, Clallam, Clark, Cowlitz, Douglas, Ferry, Grant, Kittitas, Lincoln, Okanogan, Skamania, and Wahkiakum]

Please note that Amerigroup has changed their name to Wellpoint.

Community Health Plan of Washington (CHPW)

www.chpw.org

[Coverage Area Includes All Counties except Clallam, Columbia, Garfield, Jefferson, Klickitat, Lincoln, Mason, Skamania, and Whitman]

No updates at this time.

Coordinated Care

Sherry Bennatts, Senior Manager of Case Management

www.coordinatedcarehealth.com

No updates at this time

Molina Healthcare of Washington

Kelly Anderson, MBA, BS, Rn, CCM

www.molinahealthcare.com

No updates at this time.

UnitedHealthcare

Cassie Mitson, RN, CPN

www.uhc.com

[Coverage Area Incudes: All Counties except Clallam, Cowlitz, Garfield, Pend Oreille, San Juan, Skagit, and Whatcom]

No updates at this time.

Partner Updates

Washington State Parent to Parent Network

Tracie Hoppis, Manager

Annual Parent to Parent Coordinator's training (in-person) in May a success with over 40 Coordinator's in attendance; Partnering with DOH/CYSHCN and PAVE to offer Type 1 Diabetes family support project; P2P/Arc of WA working to get 2024-2025 contracts out to 27 programs supporting all 39 Washington Counties- this year's funding will include a small increase for each program thanks to the Developmental Disabilities Administration.

<https://arcwa.org/parent-to-parent/>

Washington State Medical Home Partnerships Project for CYSHCN

Kate Orville

www.medicalhome.org

University of Washington CSHCN Nutrition Project at CHDD

Mari Mazon, MS, RDN, CD and Sarah Harsh, MS, RDN, CD

No updates at this time

Washington State Fathers Network (WSFN)

Matthew Rickmon, Director

www.fathersnetwork.org

No updates at this time

Family to Family Health Information Center (F2FHIC)

Jill McCormick

www.familyvoicesofwashington.com

No updates at this time.

Open Doors for Multicultural Families

www.multiculturalfamilies.org

No updates at this time.

Washington Autism Alliance & Advocacy (WAAA)

www.washingtonautismadvocacy.org

No updates at this time.

Office of Superintendent of Public Instruction (OSPI)

www.k12.wa.us/HealthServices/default.aspx

No updates at this time

[Back to top](#)

Seattle Children's Hospital

www.seattlechildrens.org

No updates at this time.

Lifespan Respite Washington (LRW)

Linda Porter

www.lifespanrespitewa.org

No updates at this time.

WithinReach

www.withinreachwa.org

No updates at this time.

State Updates

Department of Children, Youth, and Families

Early Support for Infants and Toddlers (DCYF-ESIT)

Lori Holbrook

www.dcyf.wa.gov/esit

No updates at this time

DSHS, Fostering Well-Being (FWB)

Autumn Wade, Amanda McCleskey, Jesenia Stark, and Kyser Corcoran

No updates at this time

DSHS, Developmental Disabilities Administration (DDA), Waiver Unit

Training Opportunity: House Bill 2008 - Intake and Eligibility Changes

Are you interested in hearing about the changes to Intake & Eligibility due to House Bill 2008, and other related WAC changes? Come join us for one of these information sessions! We will cover the removal of IQ from eligibility criteria, age requirements and other exciting changes.

We are offering three opportunities for you to come and learn. ASL interpreters will be available for all sessions.

- October 28, 2 - 4 p.m. - [click here to join the meeting](#).
- October 29, 9 to 11 a.m. - [click here to join the meeting](#).

November 4, 1 - 3 p.m.- [click here to join the meeting](#)

DSHS / DDA, Medically Intensive Children's Program

No updates at this time

DCYF, Family & Community Supports, Division of Partnership, Prevention and Services
Marilyn Gisser, Primary & Community Prevention Specialist

No updates at this time

DSHS / ALTA, Kinship Care and Lifespan Respite

No updates at this time

www.dshs.wa.gov/kinshipcare

No updates at this time.

DOH Screening and Genetics Unit
Nini Shridhar, State Genetics Coordinator

No updates at this time

Health Care Authority

No updates at this time.

Attachments

- Agenda ([PDF](#)) (wa.gov)
- Meeting presentation slides ([PDF](#)) (wa.gov)
- Meeting recording ([youtu.be](#))

Next Meeting

January 9, 2025

Virtual Meeting