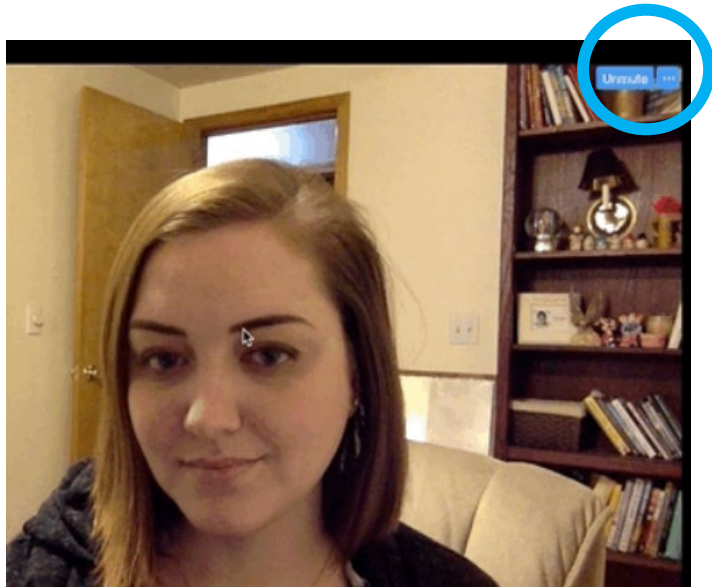


Welcome to the COMM NET Meeting



- ✓ Click the 3 dots in the top right of your image
- ✓ Select RENAME
- ✓ Enter...
 - ✓ First name,
 - ✓ Pronouns,
 - ✓ Your organization/agency name
- ✓ If you don't see your image, check your view settings at the top of the bar and set to see all webcams or Side-by-Side Gallery View
- ✓ Please make sure you are **muted**, and your **camera is turned off** if not speaking.

Spotlighted Sign Language Interpreters

For those needing sign language interpreters, we have spotlighted them. Their names are Sabrina and Lisa.

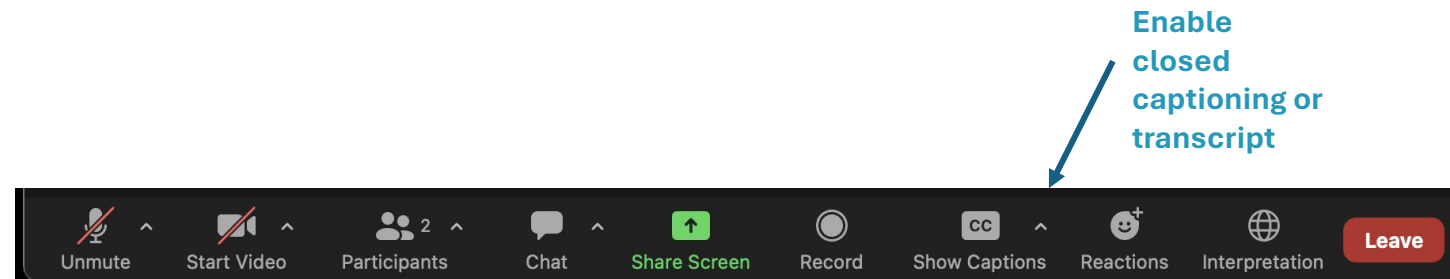
Please send a direct message to Linda Ramirez if you have any issues.

During this meeting...

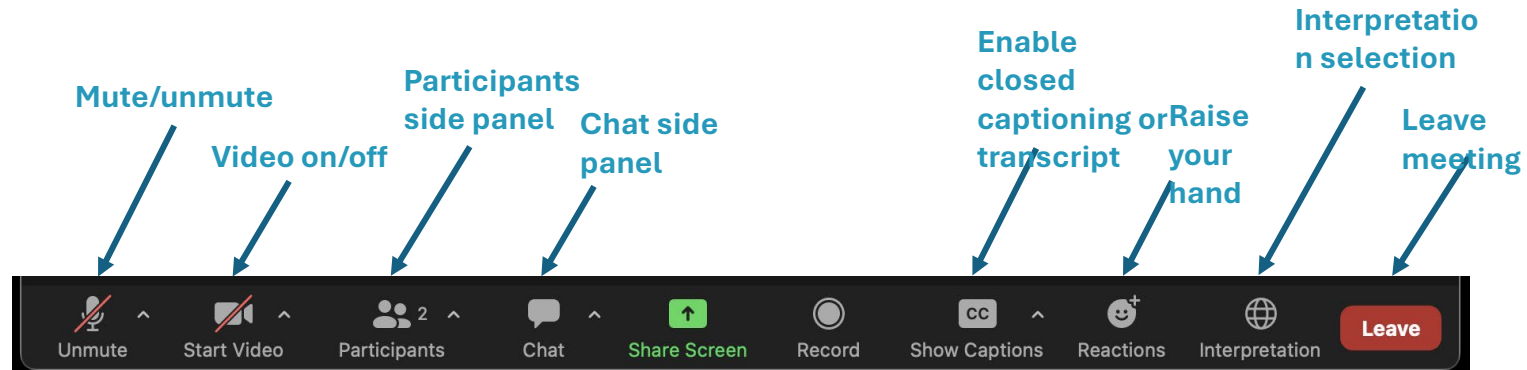
- Speak loudly and clearly
- Speak at a moderate pace
- Please avoid idioms, jargon, and technical vocabulary
- State your name when you start speaking for our interpreters

Captions and Transcript

- To view live captions, click on the menu arrow next to the Closed Caption button.
- Choose from showing subtitles, a full transcript, or both.
- You may adjust the size of the captions if you wish.
- You can also Hide Subtitles if you do not want to see the text.



Zoom navigation



NEED HELP? For help with interpretation or other accessibility concerns, direct message Linda Ramirez.



**Thank you,
interpreters!**



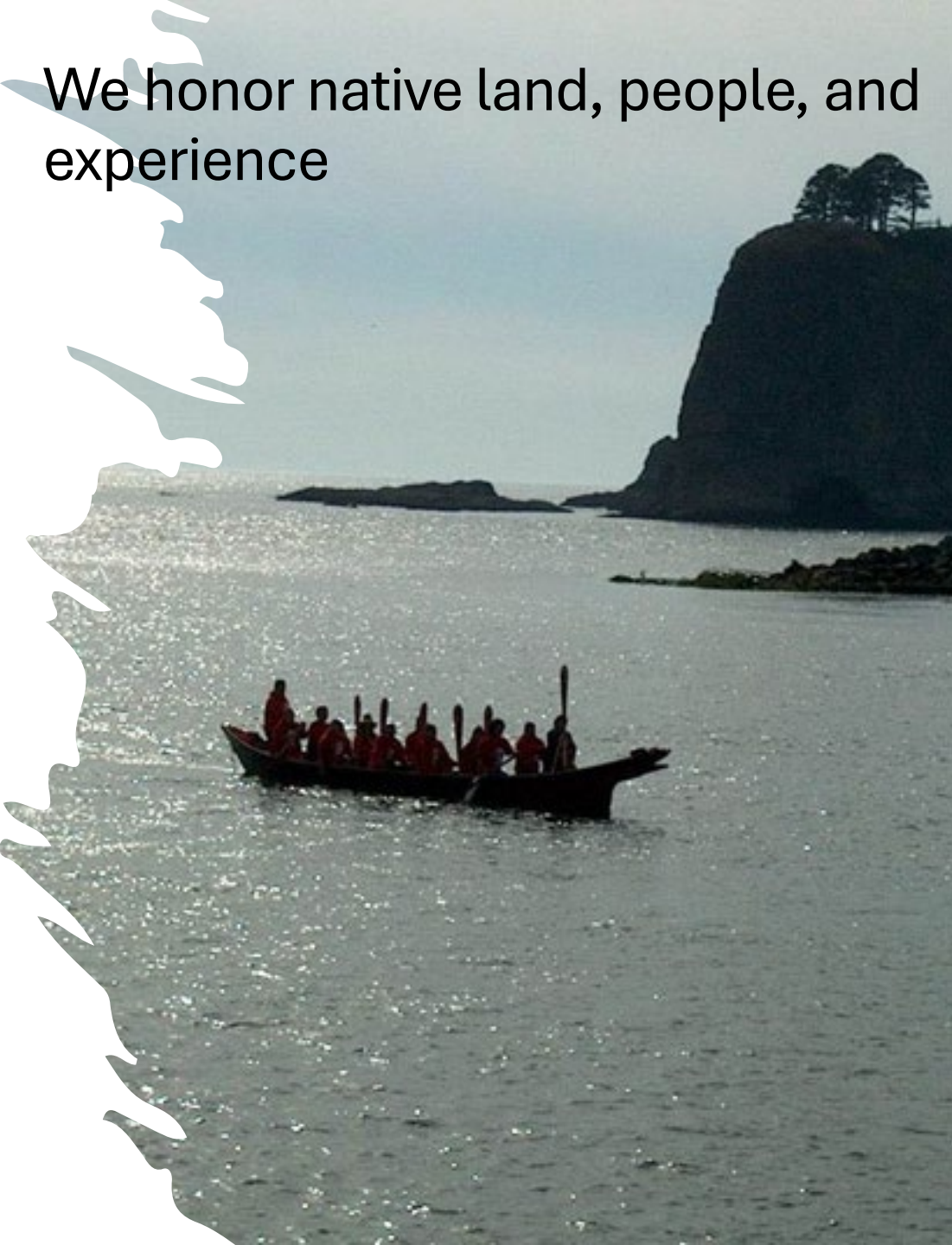
COMMUNICATION NETWORK MEETING

Children & Youth with Special Healthcare Needs – 10/10/24

Housekeeping Items:

- Please list your NAME, PRONOUNS and AFFILIATION in the chat
- Ice breaker: What is your favorite fall or holiday food that you look forward to all year round?
- If you are new, please add your email address in the chat so we can make sure you are added to our future communication network list
- This meeting will be recorded
- ASL interpreters

We honor native land, people, and experience



- The Washington State Department of Health Children and Youth with Special Healthcare Needs (CYSHCN) program recognizes and honor the original occupants and stewards of the land where we all individually and collectively gather.
- The CYSHCN program honors the survival, the adaptations, the forced assimilation, and the resilience and creativity of Native peoples—past, present, and future. We encourage CYSHCN partners to consider their responsibilities to the people and land, both here and elsewhere, and to stand in solidarity with Native, Indigenous, and First Nations People, and their sovereignty, cultural heritage, and lives.
- We also pause to recognize and acknowledge the labor upon which our country, state, and institutions are built.
- We remember that our country is built on the labor of enslaved people who were kidnapped and brought to the U.S. from the African continent and recognize the continued contribution of their survivors. We also acknowledge all immigrant labor, including voluntary, involuntary, trafficked, forced, and undocumented peoples who contributed to the building of the country and continue to serve within our labor force. We acknowledge all unpaid care-giving labor.
- To the people who contributed this immeasurable work and their descendants, we acknowledge our/their indelible mark on the space in which we gather today. It is our collective responsibility to critically interrogate these histories, to repair harm, and to honor, protect, and sustain this land.

**This land acknowledgement is adapted from Seattle Colleges*

Please share the people you honor of the land you are occupying in the chatbox
[Native-Land.ca](https://www.native-land.ca) | [Our home on native land \(native-land.ca\)](https://www.native-land.ca)

Agenda:

Time	Topic	Presenter
9:00-9:30	Welcome, Agenda, Program Updates	Nikki Dyer, DOH
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
12:00-1:00	Open Networking Hour	ALL

DOH-CYSHCN Team:



Monica Burke, PhD
CYSHCN Program Director



Nikki Dyer, MA Ed
Family Engagement Specialist



Linda Ramirez
CYSHCN Communications & Early Childhood Consultant



Khimberly Schoenacker, RDN, CD
CYSHCN Nutrition Consultant



Amanda Simon, MPH, CTRS
Process Improvement Specialist

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



Critical Areas for a Well-Functioning System

Updates Continued:

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.

Early Childhood and Communication

- New quarterly GovDelivery CYSHCN Communication Network newsletter! Sign up here: [Washington State Department of Health \(govdelivery.com\)](https://www.govdelivery.com/accounts/WA-DOH)

Updates Continued:

CHIF

- 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.

Updates Continued:

Nutrition

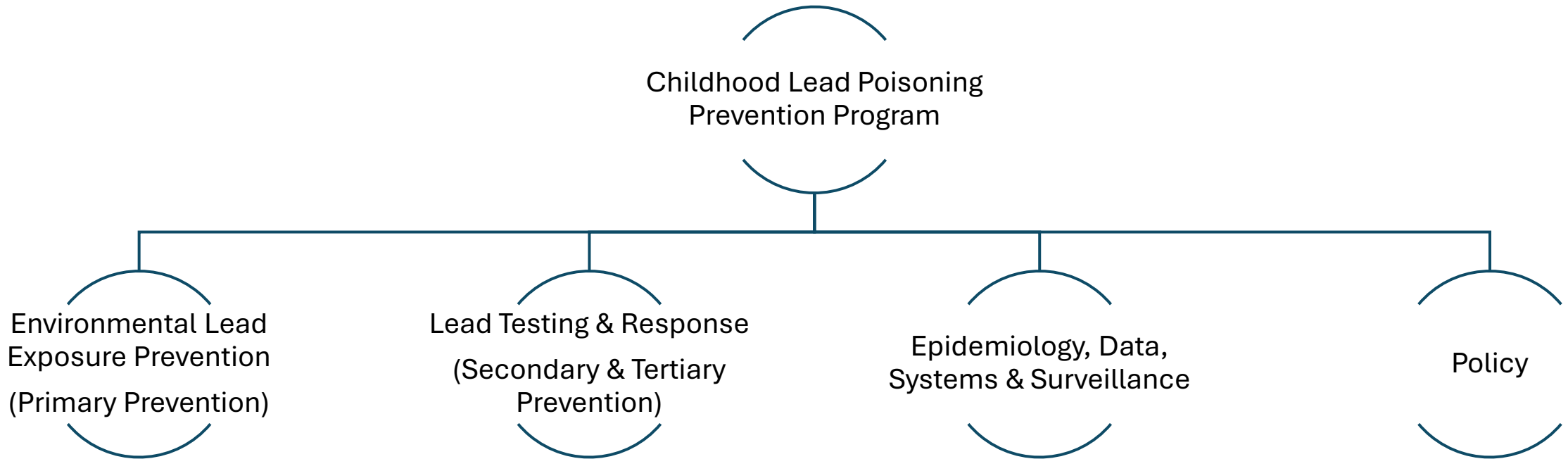
- Coming soon! Eating disorder guide created in partnership with Youth Advisory Council (YAC) nutrition subcommittee, check [Teen Health Hub WA | Washington State Department of Health](#) in 1-2 months
- [Empowering Culinary Exploration: Tips for Teaching Cooking Skills to Youth with Disabilities](#) 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](#)



CHILDHOOD LEAD POISONING PREVENTION PROGRAM

Office of Environmental Public Health
Sciences, Heathy Homes & Communities
10/10/24

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

Agenda

- General Lead Information
- Testing for Lead Exposure
- Case Response
- Resources and Contacts
- Time for Questions



Lead



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.

Brain— Affects IQ at low levels, potential hearing loss, attention and behavioral issues.

Hormones— Can impact Vit D, growth, maturation, bones and teeth.

Stomach— Sometimes causes abdominal pain and cramping.

Reproductive— May lower count and damage sperm, crosses through placenta during pregnancy and may enter breastmilk during lactation.

Heart— Potential for high blood pressure in adults.

Blood— Can limit hemoglobin production, may reduce oxygen, cause anemia, shortness of breath, fatigue.

Kidneys— Inflammation in chronic exposure.

Bones— Potential impaired development and growth, stored here and can be released in adulthood.



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



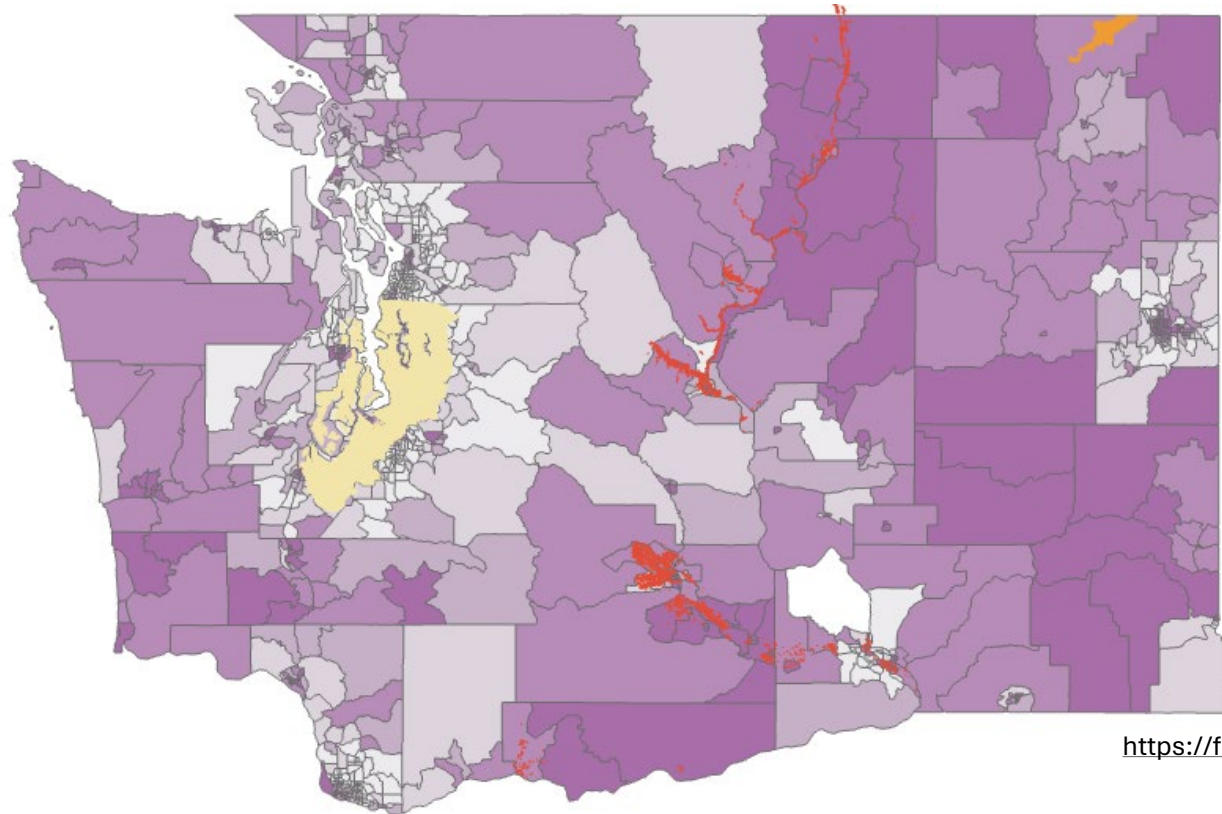
Potential Sources of Lead Exposure Continued

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.

Legend

- Historical Orchards
- Upper Columbia Plume
- Tacoma Smelter Plume

Lead Risk - WTN

- 1-2
- 3-4
- 5-6
- 7-8
- 9-10

<https://fortress.wa.gov/doh/wtn/WTNIBL/Map/LeadRisk>

Testing for Lead Exposure



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.

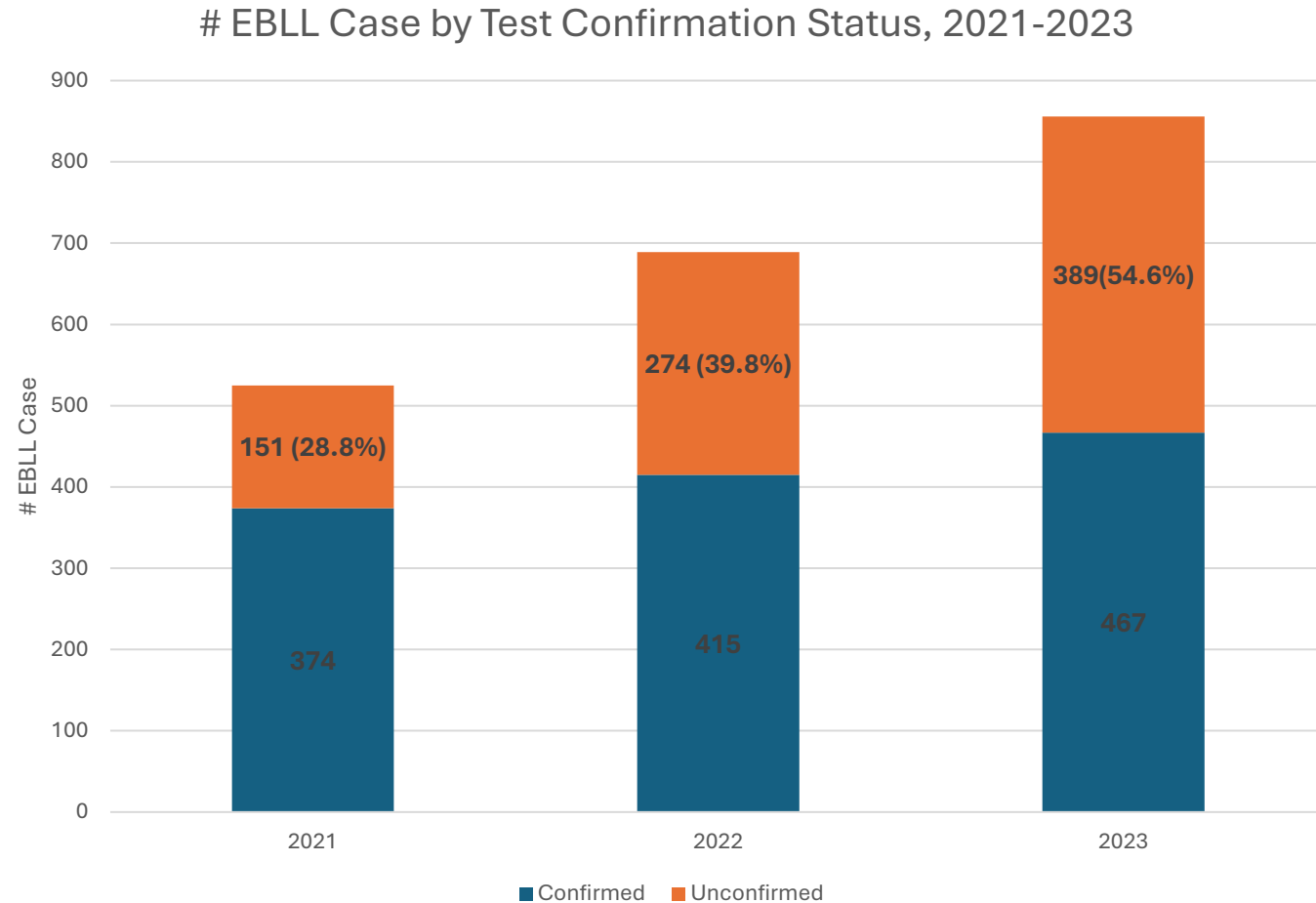
Testing Methods

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)



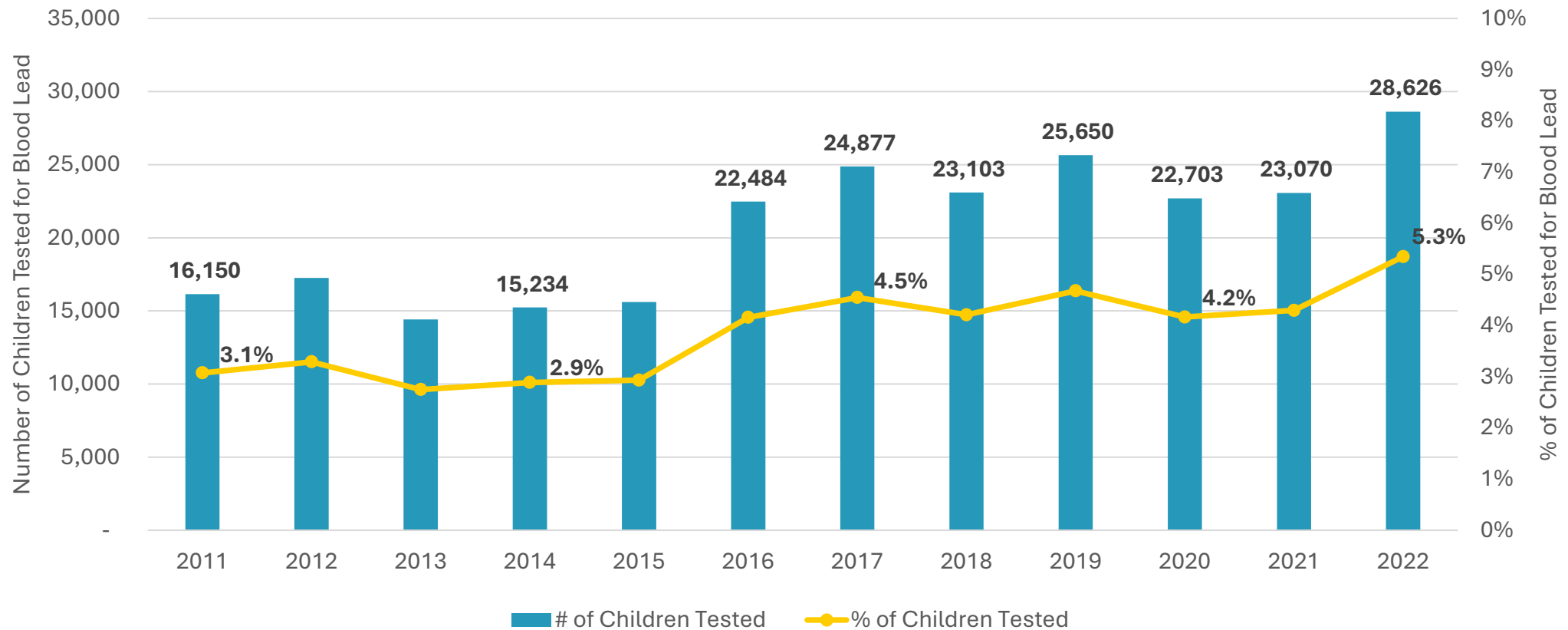
Data: Number of Cases by Test Confirmation Status



*EBLL = Elevated Blood Lead Level $\geq 5\mu\text{g/dL}$

Data: Lead Test Number and Rate

Number and Percent of Children 0-5 Years Old Tested for Lead in Washington State, 2011-2022



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.



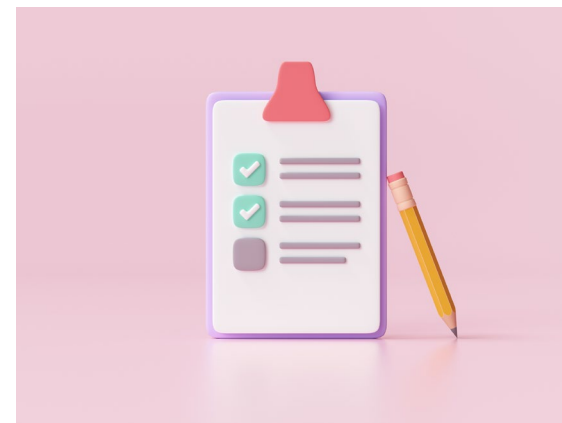
Case Response



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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



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- 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:
 - Share information
 - Coordinate messaging to families to avoid confusion
 - 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>



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Questions?

Lead Publications

Does your child need a lead test?

Does your child . . .

Yes No

- live in or regularly visit a home built before 1978, especially if it has had recent repairs?
- have a sibling or friend with an elevated blood lead level?
- have a parent or caregiver who works with lead, either at their job or their hobby?
- come from a country outside the U.S.?
- use traditional remedies or cosmetics, such as greta, azarcon, or kohl?
- have Apple Health/Medicaid?

If you answered YES to any of these questions or if you think your child has had any contact with lead, **your child needs a blood lead test.**

Tear off the card below and give it to your child's doctor at your next well child visit. If your child has Apple Health insurance, take advantage of their no-cost testing, even if you answered NO to other questions.

My child needs a blood lead test.
 Provider: A lead risk factor questionnaire identified this child as having one or more risk factors for lead exposure.
 Federal law mandates that all children enrolled in Medicaid are required to get blood lead tests at ages 12 and 24 months.
 For more information, visit doh.wa.gov/lead.

Lead Test Card

Has your child been tested for lead?



Children who have been exposed to lead usually do not look or act sick. A blood lead test is the best way to find out. Ask your health care provider about getting your child tested for lead today.

To learn more about childhood lead exposure, talk to your health care provider or visit www.doh.wa.gov/lead.

Childhood Lead Poisoning Prevention Program

DOH 311-019 June 2023
 To request this document in another format, call 1-800-525-0127.
 Deaf or hard of hearing customers, please call 711 Washington Relay or email dohe@doh.wa.gov

Lead Testing Poster

WASHINGTON STATE DEPARTMENT OF HEALTH
Lead and Your Child
 Childhood Lead Poisoning Prevention Program

QUICK GUIDE



Understanding How Lead Affects Your Child

What are the symptoms of lead exposure?
 Children who have been exposed to lead may not look or act any different. A blood test is the best way to tell if your child has been exposed to lead.

How can lead hurt my child?
 Even at low levels, lead can hurt your child. Lead affects many parts of your child's body, especially the brain. Children under the age of 6 are most at risk for the harmful effects of lead.

Lead can cause:

- Difficulty with learning and attention
- Problems with hearing and speech
- Delayed growth and development
- Behavior problems like hyperactivity and aggression

Where did my child get exposed to lead?
 Children can get exposed to lead by breathing it in or by eating it. The most common source for child lead exposure is from lead-based paint in homes built before 1978. Old lead paint can rub off and become tiny particles of dust a child may breathe in or eat when it gets on their hands or other objects they put in their mouths. Sometimes paint can come off in larger chips, which some children may put in their mouths. The lead dust and chips can even get into the soil around older homes and buildings, or where an old building once stood.

Other sources of lead include:

- Soil near old industrial sites, former orchard lands, and heavily traveled roads
- Drinking water that goes through lead pipes or plumbing fixtures with lead
- Lead passed to a fetus during pregnancy or to an infant through breastmilk
- Particles of lead carried home from a family member's work or hobby
- Some metal or painted toys or costume jewelry
- Some traditional remedies or cosmetics
- Some imported ceramics and aluminum cookware

Help your child's brain growth
 While exposure to lead can harm your child's brain, that doesn't mean it always will. You can take steps to help improve your child's brain development.

Have your child get regular developmental screenings to make sure they are meeting their milestones.

To have your child screened, talk with your doctor, or call the Help Me Grow Washington Hotline at 1-800-322-2588.

Contact us:
 1-800-909-9898
lead@doh.wa.gov
doh.wa.gov/lead

HEALTH

Lead and Your Child – Family Quick Guide

References

[Lead | Washington State Department of Health](#)

[healthychildren.org](https://www.healthychildren.org)

[No Level is Safe: Childhood Lead Poisoning and Prevention for Pediatric CHWs in Washington](#)

[Lead | Breastfeeding | CDC](#)

[Pregnant Women | Lead | CDC](#)

[Low-level lead-induced neurotoxicity in children: an update on central nervous system effects - ScienceDirect](#)

[A clinical study of the effects of lead poisoning on the intelligence and neurobehavioral abilities of children - PMC \(nih.gov\)](#)

[Protect Against Lead Exposure with WIC Foods | WIC Works Resource System \(usda.gov\)](#)

[Community Partners • Help Me Grow WA](#)

Contacts

Child Lead Prevention and Response Program Supervisor - Mary Dussol/
Mary.Dussol@doh.wa.gov

Case Management Coordinator - Amy Bertrand/
Amy.Bertrand@doh.wa.gov

Testing Promotion Coordinator - Renee Bailey/ Renee.Bailey@doh.wa.gov

Partnership Coordinator - Kristina Somday/ Kristina.Somday@doh.wa.gov

Medicaid Coordinator - Mary Buchanan/ Mary.Buchanan@doh.wa.gov



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Family Engagement
in Systems Change

FAMILY  VOICES[®]

The Family Engagement in Systems Assessment Tools

Promoting Meaningful and Equitable Family Engagement in
Systems-Level Change

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.

Why engage families?

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



3

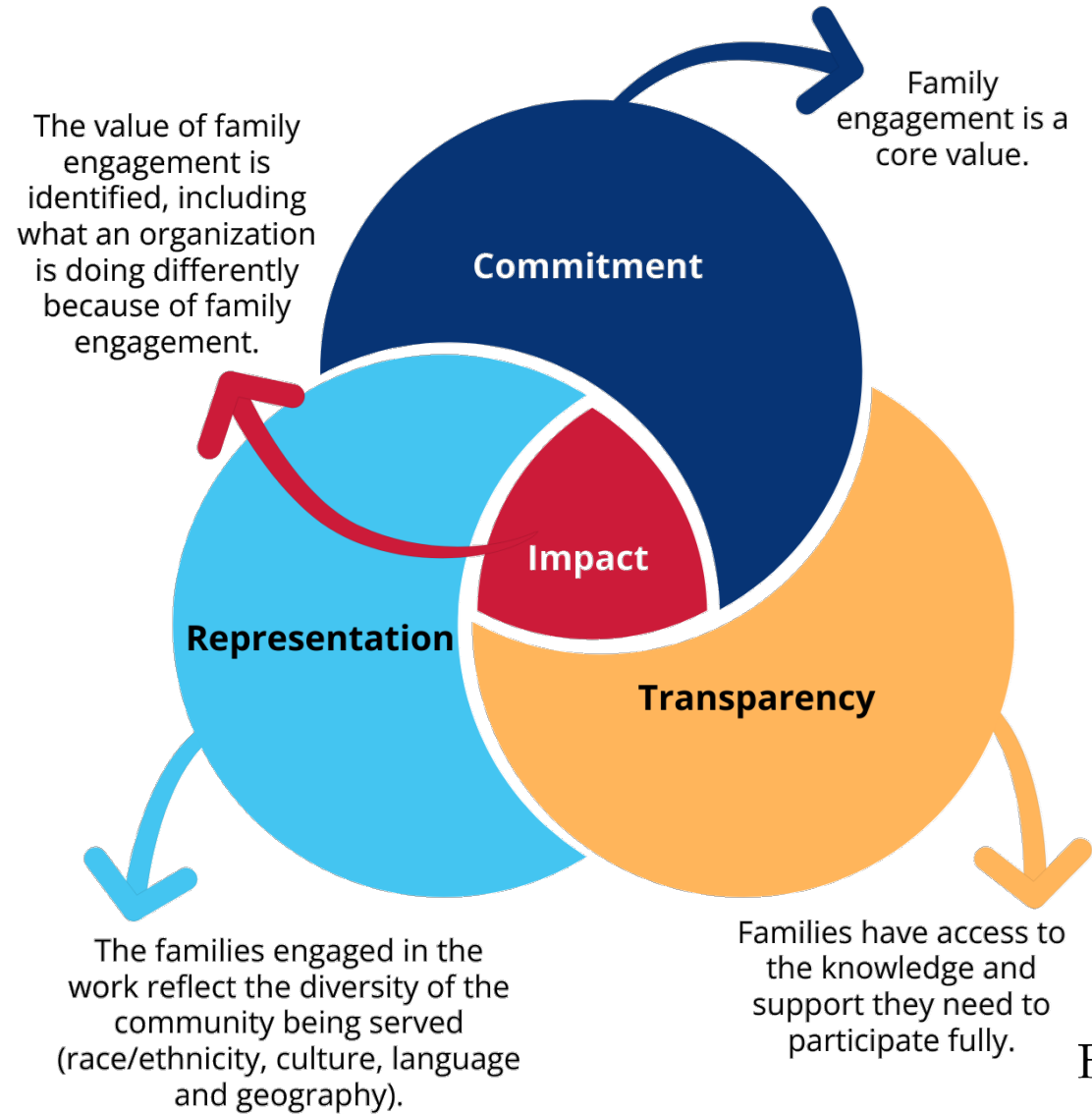
Systems Level

Collaboration to create policies, practices, and systems that improve the lives children and families

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

Domain 1: Commitment	Yes	No	Some what	Don't know
The organization uses written policy that requires family engagement in systems-level initiatives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization has one or more champions of family engagement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization acknowledges the contributions family leaders make to systems-level initiatives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization's budget includes funding for family leaders' time and/or other costs they incur (for example, travel, child care).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization provides adequate time for staff to implement changes that result from family engagement in systems-level initiatives (for example, educating staff about new policies).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Domain 2: Transparency	Yes	No	Some what	Don't know
The organization conducted activities to understand the issues faced by the children and families they serve (for example, used data or conducted a focus group).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all staff and families have a clear understanding of the initiative they will work on together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization provides the supports families and staff need to understand their partnership role (for example mentors/coaching).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all participants have the supports they need to participate in meetings (for example, physical access, interpreters, time away from other work responsibilities).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all participants have the information they need to participate in meetings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Domain 3: Representation	Yes	No	Some what	Don't know
Family leaders are representative of the races and ethnicities of the populations served by the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family leaders are representative of the cultures of the populations served by the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family leaders are representative of the languages spoken by the populations served by the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family leaders are representative of geographic areas in which populations served by the initiative live.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>NOTE: If one or more of the four demographic characteristics in Domain 3: Representation, do not match your priorities for the populations served by the initiative you are assessing, you can replace them with criteria that do match your priorities. For example, your organization may be looking for family leaders of certain ages, disabilities, gender, etc.</p>				
Domain 4: Impact	Yes	No	Some what	Don't know
Organization staff listen to family leaders' ideas.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff engage family leaders in choosing goals for the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff work together with family leaders to implement the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff work together with family leaders to evaluate the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff use family leaders' input to improve the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff can explain how family leaders contribute to the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.

Use 2: Assess Family Engagement

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.

Use 3: Improve Family Engagement

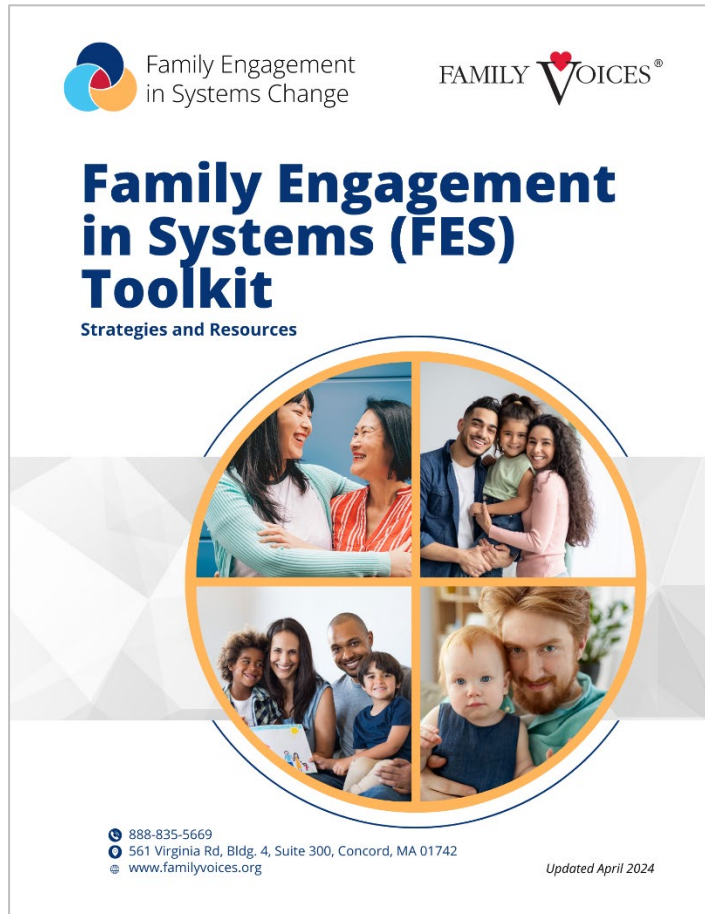


- The FESAT is a tool staff and families can score to improve family engagement in systems.
- You may want to begin by completing the FESAT for a specific initiative.

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.



Family Engagement
in Systems Change

FAMILY VOICES[®]

Thank you!



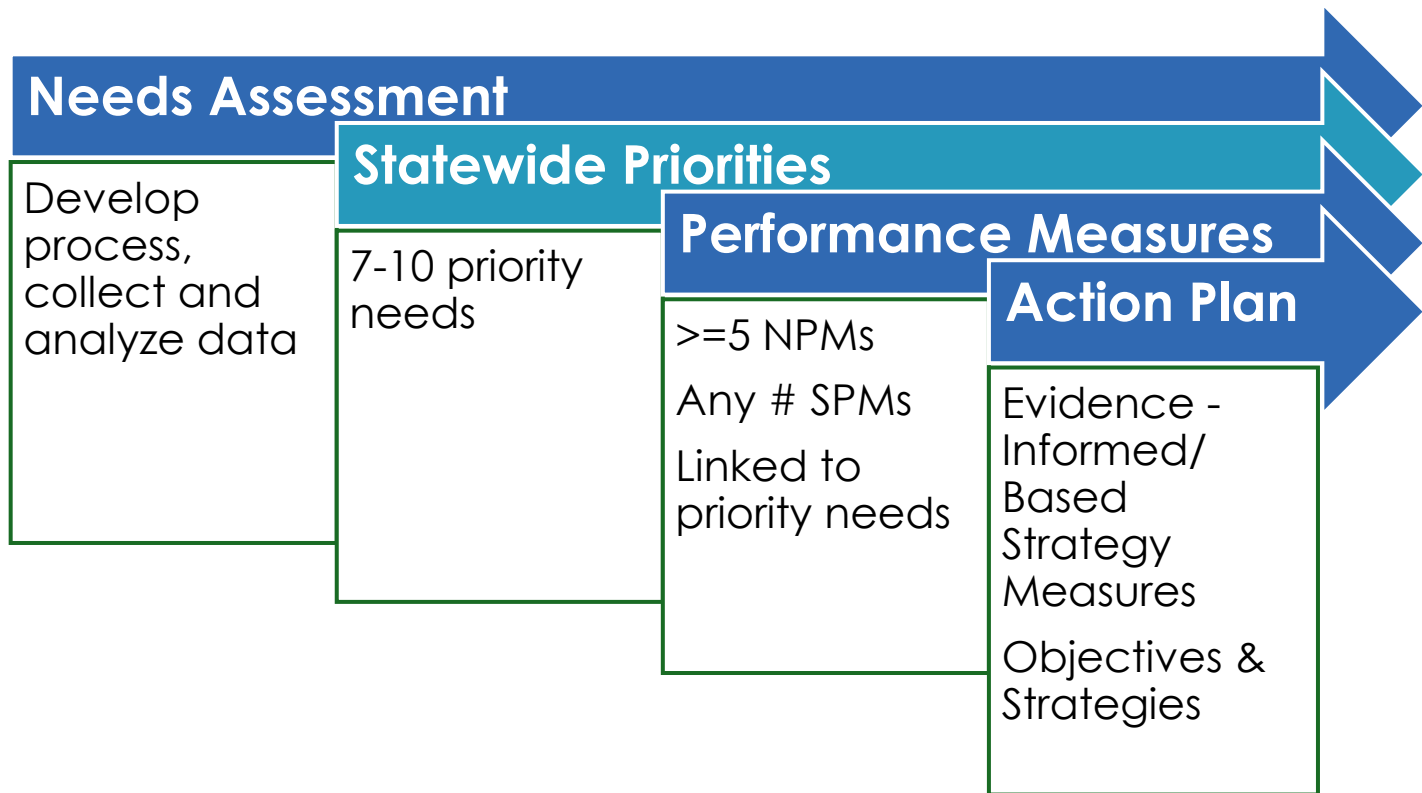
10-MINUTE BREAK

Please return by 11:00



NEEDS ASSESSMENT

Children and Youth with Special Health Care Needs



Maternal and Child Health Needs Assessment
Major Milestones

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**

All Domains





Early Observations Across the State

DISCOVERY SURVEY PARTICIPANTS AND SUMMARY ANALYSIS

Discovery Survey and Summarization

Open Fall 2023 - Spring 2024

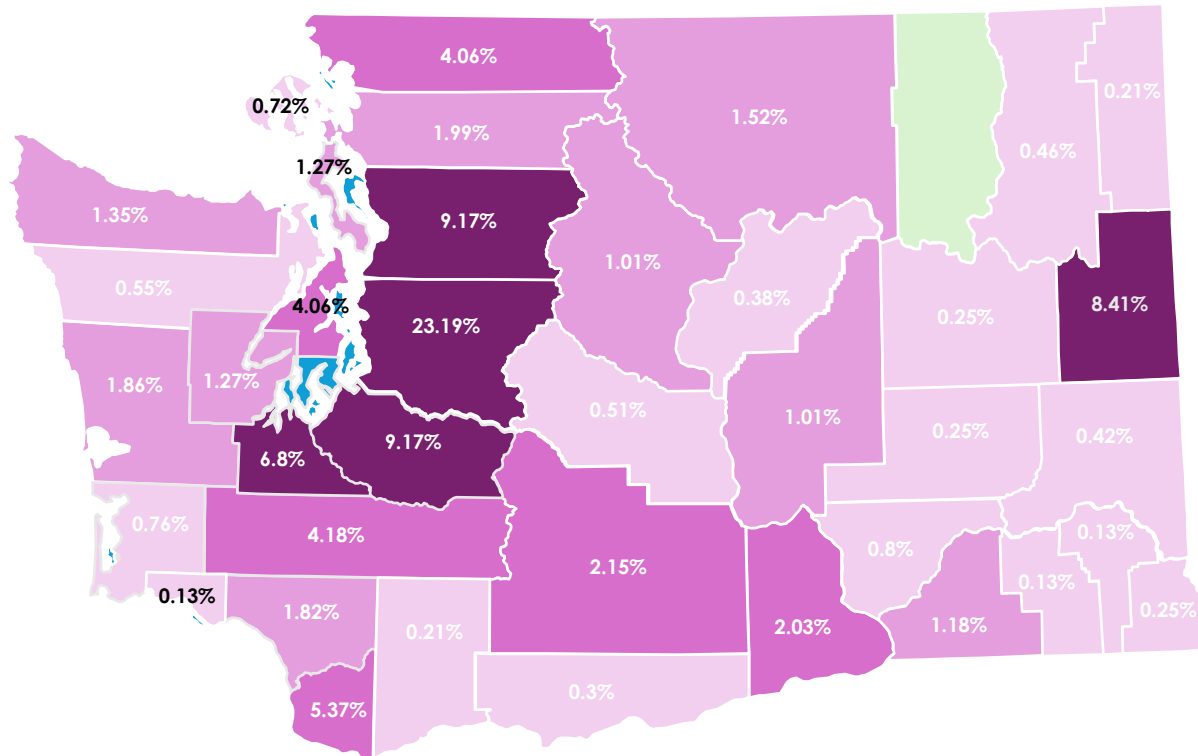
Questions we asked:

- 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-Specific Themes

Population: BIPOC

Needs and inequities that BIPOC families experience

Need

Improved, culturally responsive and culturally matched care, especially **maternal healthcare**

Collaboration and community support for equity work

Inequity

Disparities in infant mortality among AI/AN, Black and NH/PI birthing people

- 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

Immigration reform and health coverage for people who are undocumented

Access to education and job training regardless of immigration status

Jobs that offer benefits, fair wages, and respect workers rights

Care-centered

Culturally matched care and services available in people's native language



Servicios en Español para que nos puedan **atender bien, sin maltratarnos o hacernos sentir incomodos.**

English: Services in Spanish so that we can receive proper care without experiencing mistreatment or discomfort.

--Spanish Discovery Survey Participant

Population: Sexually and Gender Diverse

Need for care and services for LGBTQIA+ people and families

Care

Culturally-responsive and culturally-matched access to health care, **especially mental health**

Services

Access to childcare, safe and welcoming community spaces and resources



LGBTQIA+ mental health services... resources for parents, families and caregivers... healthy racial [and 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

Rural living intersects with identities like immigrants, limited English speakers, and CYSHCN



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

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

Not feeling safe in their communities

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 (CYSHCN)



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

Quotes | Domain: CYSHCN



A feeding team is greatly needed for kids with feeding issues, especially those who are being followed by a maxillofacial team.
-- Key Informant Interviewee



Language access for young children – push for alternative augmentative communication (AAC) into hands for non-speaking toddlers. Caregivers getting paid for taking care of their minor children on a DDA caseload. Accessibility in all spaces – wheelchair uses, restrooms with accessible changing stations for youth/adults who need diapers.
-- Facilitated Discussion Participant

Comparing Washington with National Child Health Indicators and Rankings

Indicator	Washington		State Rank	United States	
	%	95% CI		%	95% CI
Developmental Screening ¹	37.9	(25.9-51.7)	23 rd	34.4	(32.1-36.7)
Medical visit in past year ¹	86.3	(82.6-89.3)	11 th	82.2	(81.5-82.9)
Specialist visit in past year ¹	11.3	(8.7-14.6)	36 th	12.1	(11.6-12.6)
Excellent or very good health ¹	94.3	(92.2-95.9)	2 nd	89.9	(89.3-90.5)
Flourishing ¹	85.0	(79.5-89.3)	1 st	78.4	(77.1-79.6)
Childhood poverty (< 18 years old) ²	11.4	(10.2-12.6)	5 th	16.3	(16.1-16.7)

1 National Survey of Children’s Health (NSCH), 2022

2 American Community Survey (ACS), US Census Bureau, 2022

Comparing Washington with National CYSHCN Measures

Indicator	Washington		State Rank	United States	
	%	95% CI		%	95% CI
Did not receive needed care coordination	56.0	(48.2-63.4)	49	44.4	(42.9-45.9)
Did not have a medical home	63.8	(57.3-69.7)	46	59.3	(58.0-60.6)
Did not receive services to prepare for the transition to adult healthcare	73.9	(64.7-81.4)	14	77.9	(76.3-79.4)
Did not have family centered care	20.4	(14.8-27.4)	42	17.8	(16.7-19.0)

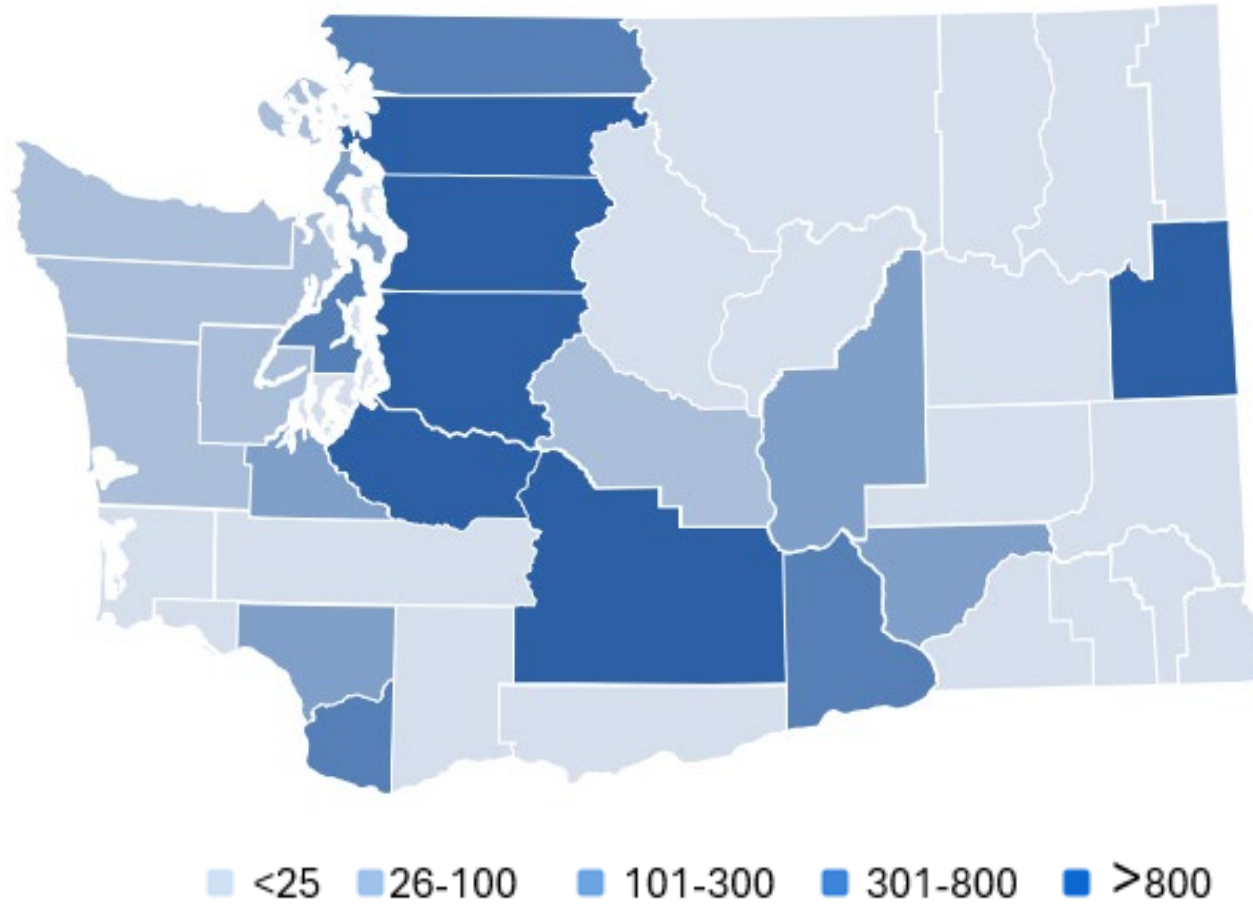
National Survey of Children’s Health,
2022

Comparing Washington with National CYSHCN Measures

Health Care Access and Quality Indicators	Washington		United States	
	%	95% CI	%	95% CI
Did not have a chance to speak with a healthcare provider privately, without parent or caregiver	33.4	(24.9-43.2)	40.9	(38.9-42.9)
Did not receive both preventive medical and dental care in the past 12 months	22.7	(17.5-29.0)	27.0	(26.6-29.2)
Very difficult to get mental health treatment or counseling	32.0	(23.4-42.1)	19.0	(17.5-20.6)
Very difficult to get specialist care	13.4	(7.9-22.0)	9.1	(7.8-10.7)

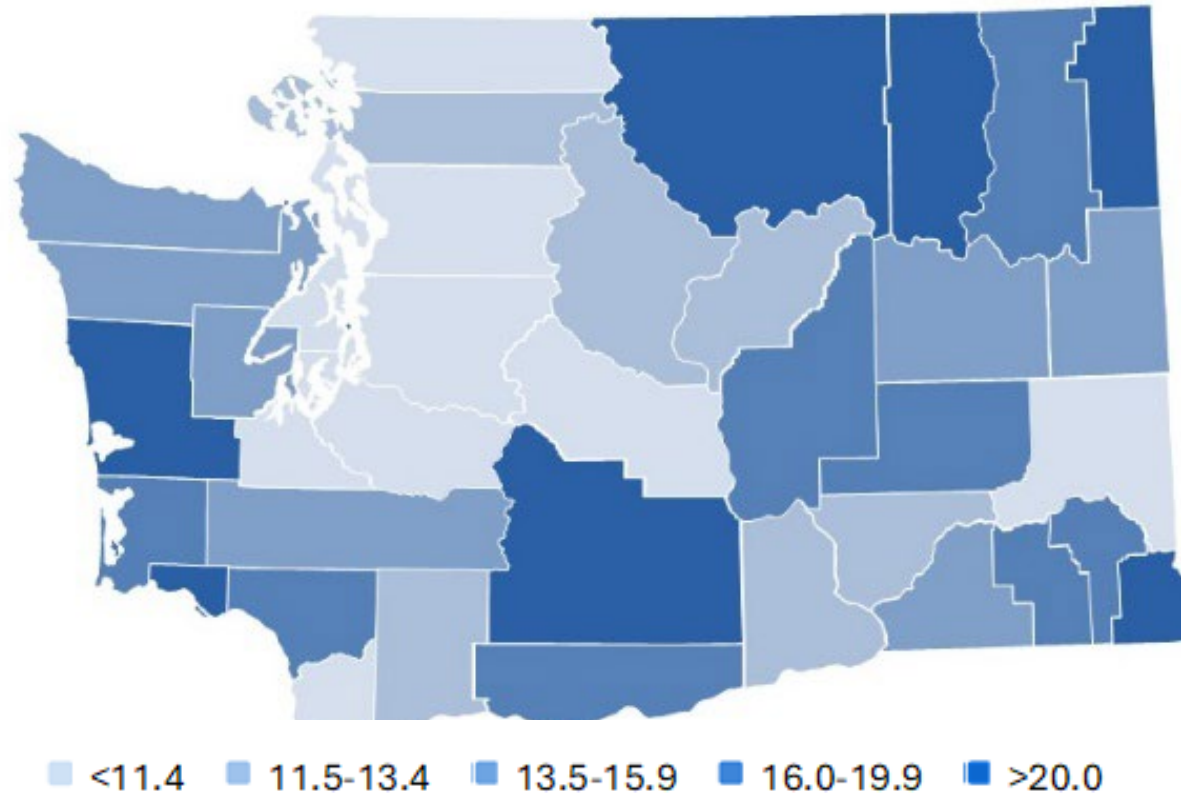
National Survey of Children's Health,
2022

CYSHCN Served by LHJs and NDCs



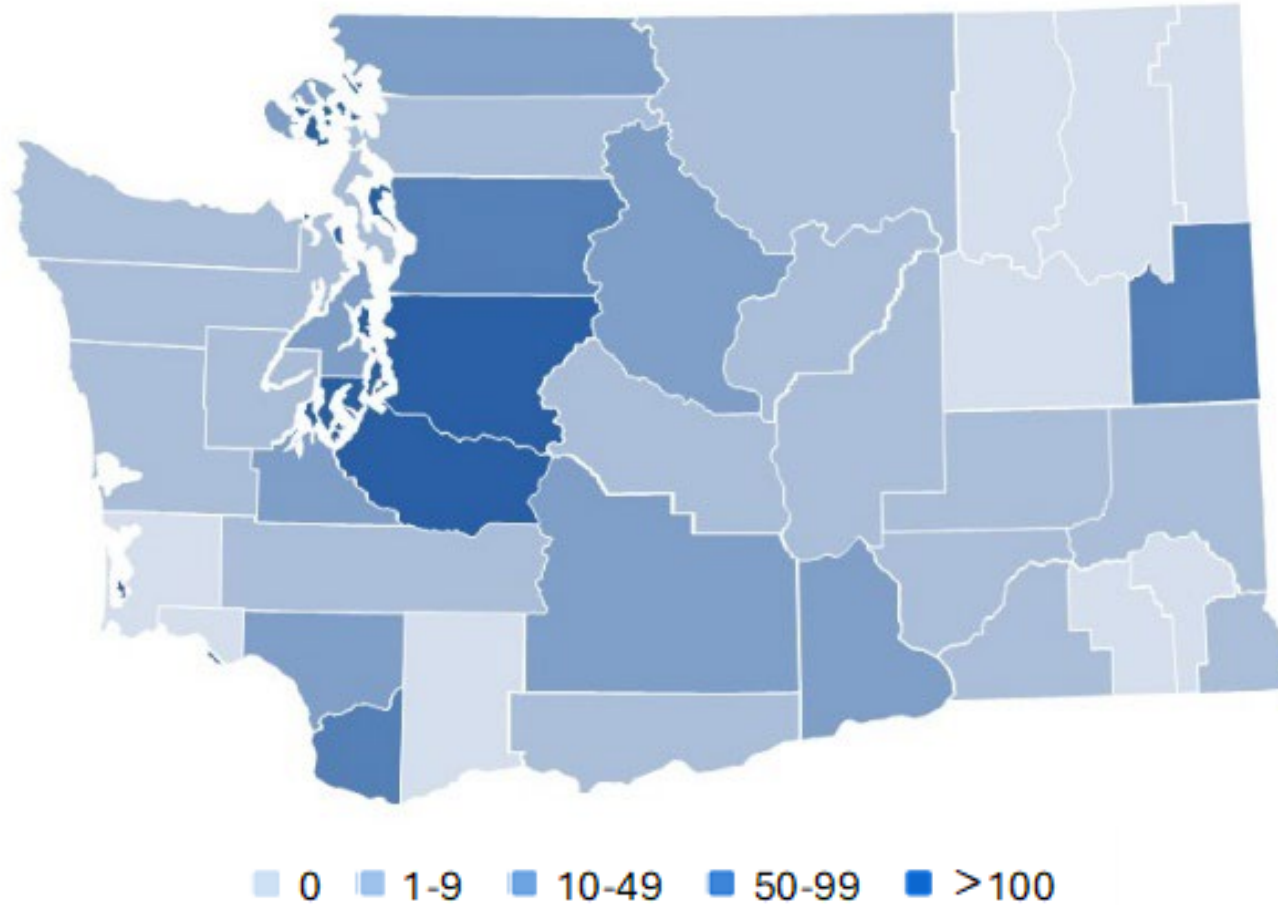
Child Health Intake Form,
2021

Percent of children under 18 living in poverty



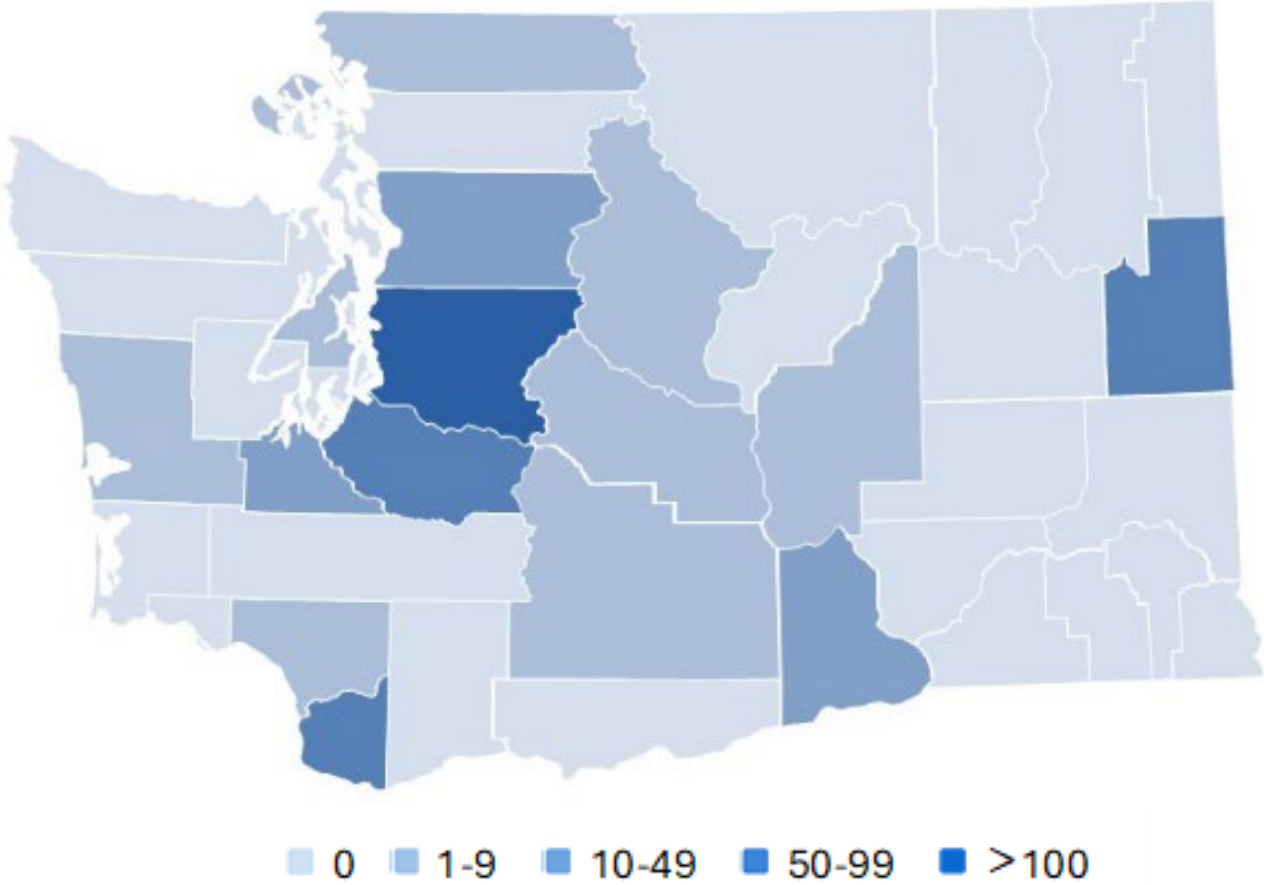
ACS, US Census Bureau, Small Area Income and Poverty Estimates, 2022

Pediatric General Providers by County



Washington Medical Commission, Physician Demographic Census Aggregate Report, 2024

Pediatric Specialists by County



Washington Medical Commission, Physician Demographic Census Aggregate Report, 2024



Impacts on Parents and Caregivers

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

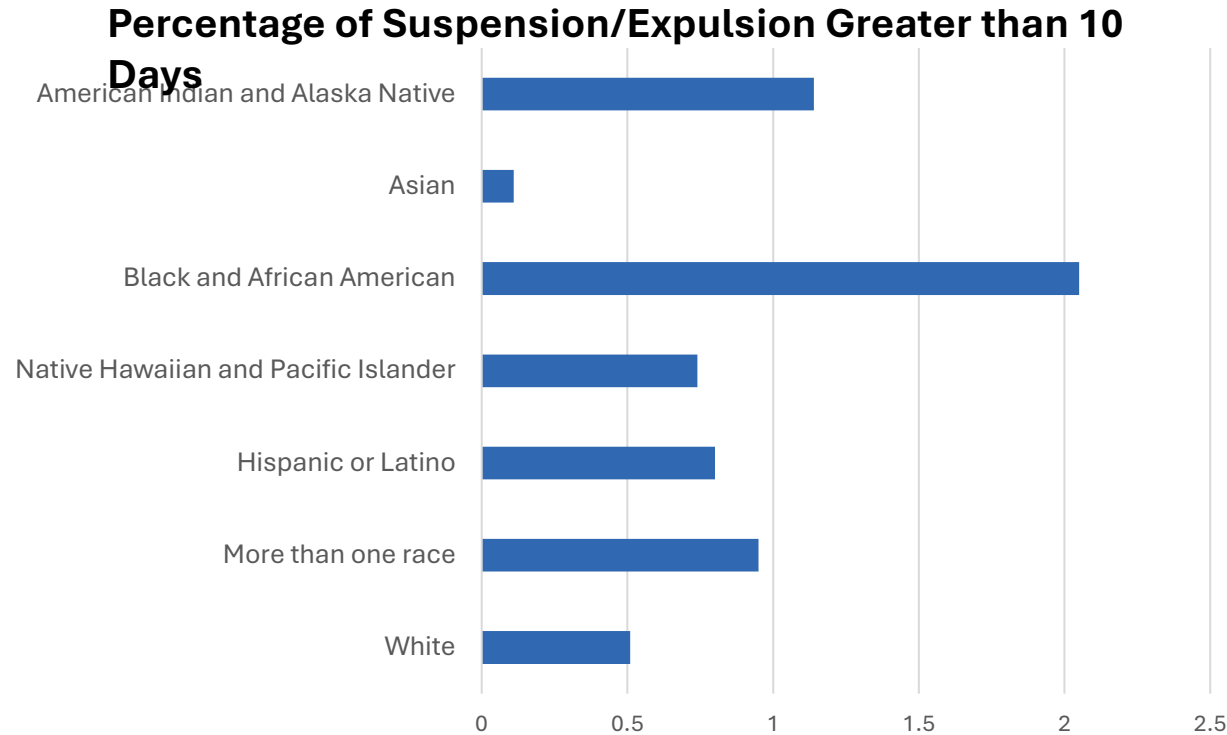
Age started special education or early intervention plan, age 1-17

Age group	Washington		United States	
	%	95% CI	%	95% CI
Less than 3 years old	15.0	(9.0-24.0)	18.3	(16.9-19.9)
3-5 years*	45.6	(35.0-56.5)	40.3	(38.3-42.4)
6-17 years*	39.4	(29.4-50.4)	41.3	(39.3-43.4)

- 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

National Survey of Children's Health,
2022

Suspensions and Expulsions for Students with Disabilities



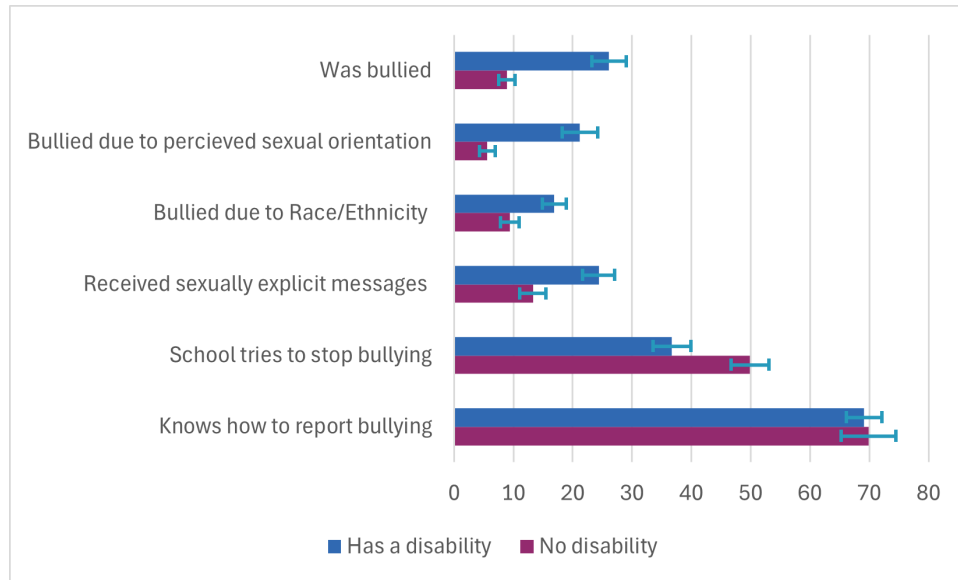
- Students with disabilities have higher suspension and expulsion rates for discipline-related incidents than those without disabilities.
- Students of color with disabilities, especially Black students, experience more disparities.

Washington State Annual Performance Report, Office of Superintendent of Public Instruction, 2022

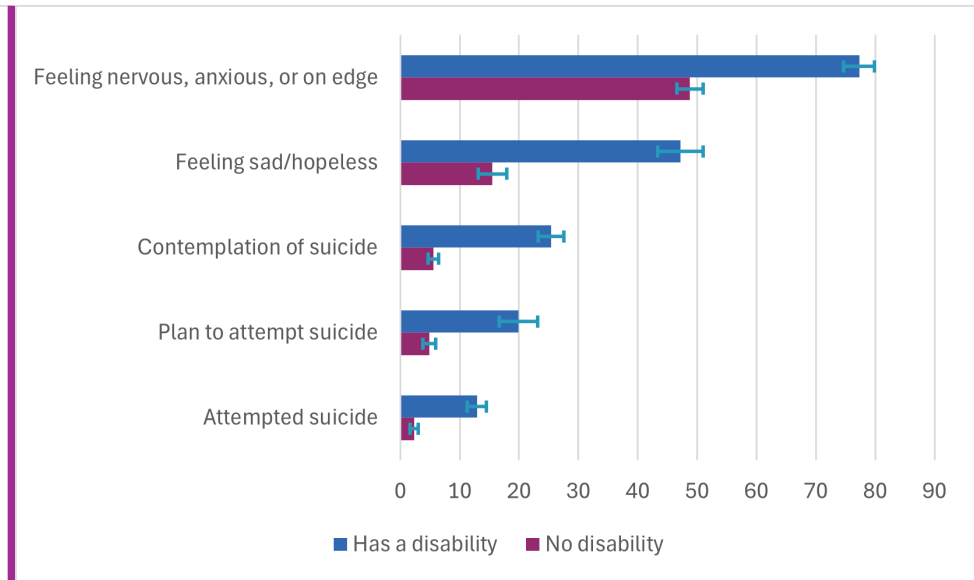
Mental Health for Students with Disabilities

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

Bullying/Harassment, Grade 10



Mental Health and Suicidality, Grade 10



Questions?

Equity Considerations

As you rank, please consider:

Inequities

- To what extent are children and families from BIPOC, rural, disability population groups disproportionately impacted?
- To what extent do racism, poverty, and their consequences, contribute to health disparities and inequities?

Public Health Influence

- To what extent does the public health system can influence disparities and inequities?

Public Health Impact

- To what extent could focusing on this theme as a public health system help reduce health disparities?

Theme Ranking for CYSHCN

Rank the listed themes from 1 to 5, with 1 being the top priority

- CYSHCN provider shortages
- Access to childcare, caregivers, respite care
- Policies to provide financial support for CYSHCN and caregivers
- Availability of sensory-friendly, ADA accessible, and CYSHCN-friendly recreational spaces
- Access to services and supports, like transportation for rural families and caretakers
- Other: please describe

Closing and Next Steps:

- Meeting Minutes and Recording will be available in the coming weeks
 - Please fill out [evaluation](#)
 - Please fill out [form](#) with any program updates
 - Send questions or additional info to Linda:
Linda.Ramirez@doh.wa.gov



To request this document in another format, call 1-800-525-0127. Deaf or hard of hearing customers, please call 711 (Washington Relay) or email civil.rights@doh.wa.gov.