



Children & Youth with Special Health Care Needs

www.doh.wa.gov/cyshcn

COMMUNICATION NETWORK MEETING

July 11, 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.

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Attendees

Due to continued social distancing requirements enacted by Governor Inslee, Communication Network will be conducted entirely in an online format.

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Camille Schultz, WithinReach	camilles@withinreachwa.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.

ACE Kids Act

In the spring, the legislature passed House Bill [1941](#) to create a new [health home option for Medicaid eligible children with medically complex](#) conditions (AKA [ACE Kid Act Health Home](#)).

HCA must develop a State Plan Amendment and submit it to the Centers for Medicare and Medicaid Services (CMS) by January 1st, 2025.

They are currently consulting with CMS and the Children's Hospitals as well as our blueprint group and family advisory council as they develop the program.

MCHBG Needs Assessment

DOH is currently analyzing the results of our needs assessment. We will be presenting results and working with partners to develop our priorities for the next 5 years this fall.

Child Health Intake Form (CHIF) Database

CHIF data will continue to be collected quarterly by spreadsheet.

Please request MFT assistance via the following link- <https://www.surveymonkey.com/r/LGYDQLR>

CHIF Office Hours: 4th Wednesday of the month at 11 am.

Please direct any questions about CHIF to the CHIF Inbox- DOH-CHIF@doh.wa.gov.

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

CYSHCN Communication & Early Childhood

No update at this time

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

Washington Statewide Leadership Initiative (WSLI) and DOH Family Engagement

Published reports on information gathered during family-focused listening sessions in 2021 and 2023: [Early Childhood \(birth to 5\)](#) and [Type 1 Diabetes](#).

Supporting a Family Advisory Council on Care Coordination work July 2023-present

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

Completed 9-month FARE Pediatric Food Allergy course. What would you like to see as a resource on this topic?

[Empowering Culinary Exploration: Tips for Teaching Cooking Skills to Youth with Disabilities](#) is online. Do you want to join a quarterly meeting to share recipes and what's working?

Consider joining the T1D workgroup if this is a population of interest, we meet monthly, the 4th Wednesday at 8AM

Find all Type 1 Diabetes (T1D) workgroup flyers and resources under www.doh.wa.gov/CYSHCN listed under partners/provider

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

Renee Tinder has moved to a Behavioral Health Strategist position at DOH, we will be posting for her replacement soon.

New [study](#) on the needs of those with co-occurring I/DD and behavioral health needs

Pediatric Mental Health Care Access (PMHCA) -[SAFES](#) program actively accepting referrals

PMHCA expansion funds projects continuing with SCH ED, UW Medical Home Partnership, and Reclaiming Futures focusing on consultation with emergency departments, school-based health centers and autism assessment training/tools.

Seattle Children's Mental Health Hospital Consultation Service has launched — providing provider-to-provider consultation and resource assistance to hospitals in need of support for their mental health boarders (flyer in chat)

For more information, contact Renee Tinder at Renee.Tinder@doh.wa.gov

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	Early Hearing Detection Diagnosis and Intervention (Training Modules)	Anna Dodd, DOH EHDDI
10:10-10:50	Guide by Your Side	Christine Griffin, Hands & Voices
10:50-11:00	Break	
11:00-12:00	Plan of Safe Care & SUD Pregnancy Pilot	Camille Schultz, WithinReach

Guest Presentations

Early Hearing Detection Diagnosis and Intervention (Training Modules)

Anna Dodd, DOH EHDDI

Early Hearing Detection Diagnosis and Intervention's (EHDDI) 1-3-6 Goals

- 1 - All infants receive a hearing screen before they are ONE month old.
- 3 - Infants who do not pass two hearing screens have a diagnosis evaluation before they are THREE months old.
- 6 – Infants who have been identified as deaf or hard of hearing start early support services before they are SIX months old.

Follow-up Coordinator's role is to monitor that 1-3-6 goals are met

EHDDI Advisory Group that consists of 18 members including: healthcare professionals, parents and caregivers, Deaf adults, early support providers, individuals from other agencies

- Starting in August 2021, EHDDI Advisory Group assessed early support services in Washington
- November 2021, used the Early Hearing Detection and Intervention System Self-Assessment
- Focused on Goal 2: All children who are Deaf or Hard of Hearing (DHH) and their families experience timely access to service coordinators who have specialized knowledge and skills related to working with individuals who are DHH
- Family Resource Coordinator (FRC) is the first point of contact with the family and is the person responsible for implementing the Individualized Family Service Plan (IFSP) and coordinating with agencies and service providers.
 - They must be able to answer questions about:
 - Hearing screenings and diagnostic evaluations

- Hearing and visual technology
 - Communication opportunities
- Created training modules to improve the knowledge of FRCs
 - April 2023, contracted with Talance to create 3 online training modules
 - Created a workgroup to assist in creating the modules
 - Early Support for Infants and Toddlers
 - Center for Deaf and Hard of Hearing Youth
 - Office of Deaf and Hard of Hearing
 - Early support services providers
 - DHH service providers
 - Total Communication
 - American Sign Language
 - Listening and Spoken Language
 - Audiologists
 - Washington State Hands and Voices
 - Many individuals in the workgroup were also professional DHH adults
 - Met three times to:
 - Set learning objectives and outline and
 - Review draft content and discuss additional learning resources needed
 - Three training modules created:
 - Specialized providers and services
 - Knowledge Building
 - Bias Awareness
 - The modules are housed on the [Washington Portal](#)
 - Officially went live February 6, 2024
- Next Steps
 - Create a training about the transition from Part C to Part B services
 - Determine if there is an increase in timely referrals
 - Early support services
 - Family-to-family support
 - DHH specific services
 - Add a mechanism for learners to provide feedback to the EHDDI program

Questions and Answers:

Q: Who was the target audience for the email blast?

A: Anyone and everyone we had an email for connected to the EHDDI program, including pediatricians, FRCs, school districts, etc.

Guide by Your Side

Christine Griffin, Hands & Voices

Introduction:

Parent of 2 DHH adults – would be considered Deaf plus, meaning they have additional health needs and/or disabilities

Washington Hands & Voices Program Coordinator

EHDDI Advisory Group as a co-chair

Hands and Voices supports families

Parent driven organization and collaborative

Everyone is welcome without judgement for the decisions they make for their family and their child

Washington State Hands & Voices founded in 2007

- Collaborative group of parents and professionals
- Dedicated to supporting families with children who are Deaf or Hard of Hearing

What is Family Support?

- Support
- Information
- Modeling

Families have diverse responses to hearing that their child is DHH

- Emotional responses vary
 - Grief
 - Surprise
 - Relief at knowing what is happening
- Lifelong experience
- Not just linear

Hands & Voices offers

- Events and workshops
 - Just for Dads panel (virtual)
 - Webinar series on Infant Mental Health (virtual)
 - What's Up Wednesday (virtual)
 - Annual Summer Family Picnic on July 20, 2024
- Advocacy and leadership
 - Ongoing trainings
 - Share opportunities with staff and families
- Support programs
 - Guide By Your Side – Navigation and Support
 - Focus on well-being, knowledge, and empowerment
 - Advocacy Support and Training (ASTra) Advocates
 - Recognize impact
 - Communication options
 - Trainings and workshops
 - Advocate

Resources on website

- [Family Toolkit](#)
- [Recorded webinars](#)
- [ABCs of Advocacy](#)
- [Refer to Guide by Your Side and ASTra Programs](#)

Introduction

Parent of 3 young DHH children

Parent Guide

Located in SW Washington

Started her family's journey in a different state connected with early intervention and DHH adults

Moved to Washington State and looked for the community

Connected with Hands & Voices Parent Guide

Connected with advocacy learning opportunities and social events, like the picnic

Parent Guide shared:

- Lived experiences
- Meeting families
- Navigating birth to 3, educational, and medical systems
- Assisting with unbiased decision making
- Connecting with the Deaf Community
- Exploring amplification/listening technology
- Attending IFSP meetings
- Specific resources
- Answering questions along the way!

Questions and Answers:

Q: What is the contact for referrals?

A: Click on the "request support" button on this [webpage](#).

Plan of Safe Care & SUD Pregnancy Pilot

Camille Schultz, WithinReach

Who is Plan of Safe Care for?

- Newborns with prenatal substance exposure and their household

Background:

- Federal legislation changes starting in 2016 – updated laws regarding infants who were exposed to substances in utero
- WA two-pathway approach:
 - Child welfare – involuntary, served by DCYF
 - Community Pathway – voluntary, served by HelpMeGrow
- Two pilot sites launched in summer of 2021
 - Pierce County (South Sound 211)
 - Yakima County (Yakima Memorial Maternity Support Services)
- Help Me Grow WA identified as the community pathway in 2021

- Expertise in statewide resource navigation and specialized supports
- Partnership with birthing hospitals
 - Collaboration
 - Learnings and listening sessions
 - Progress and goals

Referral pathway for birthing hospitals

- Provider gives de-identified information
- Does include exposure type
- Determines pathway option
 - If the algorithm points to community-based pathway, the family can opt-out

Who is the Community-Based Pathway for?

Prenatal exposure to:

- **Methadone or buprenorphine as prescribed** + no safety concerns
- **Opioids as prescribed** + no safety concerns
- **Medication or combination of medication with abuse potential as prescribed** + no safety concerns
- **Cannabis** + no safety concerns

Community-Based Pathway in Action

- Consent-based
- Specialized team serving statewide
- Virtual services
- Flexible and robust outreach and follow-up
- Wraparound resource navigation
- Warm handoffs

Who is the SUD Pregnancy Pilot for?

Pregnant people with substance use disorder (SUD)

SUD Pregnancy Pilot HUB Structure

6 pilot sites serving 9 counties

Questions and Answers:

Q: Is there a way to connect with/refer families during pregnancy instead of waiting until birth?

A: CPS cannot get involved until the moment the baby is born.

Q: How do you do the wrap-around so that all the providers connected to this family know they are connected to you and supported?

A: This is a new program, we are hoping to establish a closed-loop referral system. We are still working on building a way to connect back with pediatricians and other providers that is respectful of the family's autonomy. This is intended to be a short-term resource connection, not a long-term solution or case managers.

Q: How does marijuana factor into this?

A: If there are no safety concerns identified by the algorithm, cannabis will lead to the community-based pathway option for families. They can opt out of this.

Q: Is there any out-of-county for families who give birth in a county that is different than their residence, or for families who give birth out of state?

A: HelpMeGrow serves statewide so there is no out-of-county. The two pilot sites would take people from Pierce and Yakima counties, but HelpMeGrow will serve all others.

Q: Does this come with funding for pilot sites?

A: No, not at this time. There may be an opportunity for future funding and pilot sites in the future as we expand.

Q: How is the portal de-identified?

A: There are two parts to the referral portal. The DCYF side is all de-identified. If the algorithm leads to the community-based pathway, all of that identifiable information comes to WithinReach for contact.

Q: Paid Family Medical Leave is such a confusing process. How do you help with this?

A: There is a question on our screening where we briefly explain what Paid Family Medical Leave is and what qualifies for the service. We can do the eligibility quiz, but the family does have to take it from there as it's a bigger process and individual to each family.

Q: How was the first clinic funded?

A: They do receive some funding through DCYF. Other than that, they likely piece together multiple funding streams and grants.

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.yakimachildreenvillage.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 Kauj, Lead Therapist

www.skagitvalleyhospital.org

No updates at this time

Mary Bridge Children's Therapy Services

Kari Tanta, Rehab Manager

Please check out our updated therapy resource pages:

[Rehabilitation & Therapy Services - Mary Bridge Children's](#)

Please widely share our workshops and educational opportunities for staff and families:

[Therapy Workshops & Continuing Education - MultiCare Mary Bridge Children's Hospital & Health Network](#)

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WASHINGTON STATE DEPARTMENT OF HEALTH

Mary Bridge Speech and OT Feeding Clinic (SOFE)

- A multidisciplinary clinic dedicated to pediatric feeding
- Currently offered at Mary Bridge therapy clinics in Gig Harbor, Lakewood, Olympia, and Puyallup
- Evaluations and treatments are administered by feeding specialists from speech therapy and occupational therapy
- Recommendations and follow-up care are also provided
- Types of patients:
 - Delayed oral motor skills
 - Picky eaters
 - Sensory processing disorders
 - Poor growth
 - Tube weans
 - Medically complex care
- Referrals are needed for both speech and occupational therapy for feeding
- To schedule, call: 253-697-5200

Kindering

Kathy Fortner Director of Operations

www.kindering.org

No updates at this time

HOLLY RIDGE

Alicia Skelly, Infant Toddler Program Director

No updates at this time

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/>

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

University of Washington – Center on Human Development and Disability (CHDD)

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Nutrition Training Contract <http://depts.washington.edu/cshcnnut/>

We completed our annual Nutrition Network for CYSHCN and Washington State Community Feeding Teams continuing education meeting on April 22nd and 23rd, respectively. Both were held virtually. Nutrition Network meeting was attended by 71 dietitians from 19 counties; the Feeding Team meeting was attended by 135 feeding team members from 13 counties. Both meetings received high satisfaction ratings from attendees and included topics such as how to support nutrition for children with pediatric feeding disorder/ARFID and feeding considerations for children with vision impairment.

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

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

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

No updates at this time.

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

October 10, 2024

Virtual Meeting