



Children & Youth with Special Health Care Needs

www.doh.wa.gov/cyshcn

01/17/25

COMMUNICATION NETWORK MEETING

January 9, 2025

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.....	8
Staff Updates	8
Child Health Intake Form (CHIF) Database.....	8
Washington Statewide Leadership Initiative (WSLI) and DOH Family Engagement.....	8
CYSHCN Program Nutrition Updates	9
CSHCN Rule (Washington Administrative Code-WAC) Update.....	Error! Bookmark not defined.
Essentials for Childhood (EFC).....	9
Universal Developmental Screening (UDS).....	9
MCH LHJ Contracts Updates	9
Guest Presentations	9
Developmental Disabilities Council Equity & State Plan Discussion	Error! Bookmark not defined.
Introduction to Open Doors for Multicultural Families.....	Error! Bookmark not defined.
CSHCN Coordinator Updates by County	23
Grays Harbor County Public Health	23
Grant County Health District	23
Island County Public Health	23
Jefferson County Public Health.....	23
Pacific County Children and Youth with Special Health Care Needs.....	24
San Juan County	24
Spokane Regional Health District.....	24

Thurston County Public Health and Social Services.....	24
Yakima County- Children’s Village	24
Neurodevelopmental Center (NDC) Updates	24
Peace Health Children’s Therapy - Whatcom County	24
Children’s Therapy Skagit Valley Hospital.....	Error! Bookmark not defined.
Children’s Therapy Valley Medical Center.....	Error! Bookmark not defined.
Kinderling.....	25
HOLLY RIDGE	25
Children’s Therapy Center.....	25
Health Plan Updates	25
Amerigroup-Washington	Error! Bookmark not defined.
Community Health Plan of Washington (CHPW).....	25
Coordinated Care.....	26
Molina Healthcare of Washington	26
UnitedHealthcare.....	26
Partner Updates	26
Washington State Parent to Parent Network.....	26
Washington State Medical Home Partnerships Project for CYSHCN	26
University of Washington CSHCN Nutrition Project at CHDD	27
Washington State Fathers Network (WSFN)	27
Family to Family Health Information Center (F2FHIC).....	27
Open Doors for Multicultural Families.....	28
Washington Autism Alliance & Advocacy (WAAA)	28
Office of Superintendent of Public Instruction (OSPI)	28
Seattle Children’s Hospital.....	28
Lifespan Respite Washington (LRW)	28
WithinReach.....	28
State Updates.....	28
Department of Children, Youth, and Families.....	28
Early Support for Infants and Toddlers (DCYF-ESIT).....	28
DSHS, Developmental Disabilities Administration (DDA), Waiver Unit	29
DSHS / DDA, Medically Intensive Children’s Program	29
DSHS, Fostering Well-Being Care Coordination Unit (FWB CCU)	29
DSHS / ALTA, Kinship Care and Lifespan Respite	29
DOH Screening and Genetics Unit.....	29

Health Care Authority	29
Attachments	29
Next Meeting	29

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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D'Andrea		
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Janet Wyatt, Kitsap Public Health CYSHCN Coordinator		

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Jillian Bingham		
Kaelyn Carlson		
Kara Ikeda, LEND Nutrition Trainee, UW IHDD		
Kasey Thomas, Case Manager, WLP		
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Mary Jo Schatz, Tacoma-Pierce County Health Department		
Matthew Rickmon, Washington State Fathers Network		
Megan Works RN-Island County Public Health		
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Molly Corvino. NETCHD		

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Stephanie Larsen, PHN, MCH, Cowlitz HHS		
Stephanie White, NETCHD		
Sue Adelman, UW LEND		
Susan Wendel		
Suzie Tallar, Coordinated Care		
Todd Holloway		
Tracie Hoppis, Children's Village/P2P, CYSHCN Coordinator Yakima		
Whitney Wheelock, Kittitas County Public Health		

Guests:	
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Jen Moss, Statewide Program Director for Curriculum Training and Websites Team	jen.hey@wsu.edu
Jill Walsh, Parent Perspective	jillwalsh2013@gmail.com
Leslie Elder, MSN, RN, BreatheWell Inspiration	leslie@breathewellinspiration.com

Land Acknowledgement

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.
- Many of us are occupying space from lands that are of the traditional home of the Coast Salish people, the traditional home of all tribes and bands within the Duwamish, Suquamish, Tulalip, and Muckleshoot nations.
- The CYSHCN program honors the survival, the adaptations, the forced assimilation, 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 chat [Native-Land.ca | Our home on native land \(native-land.ca\)](#)

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

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

Staff Updates

- New Learning Journey kicking off with Maternal Child Health (MCH) Workforce Development Center on Local Health Jurisdiction role in CYSHCN services and systems.
- This complements our current work on CYSHCN Blueprint implementation focused on care coordination.
- DOH MCH Surveillance and Evaluation team are continuing to work with programs on priority development as part of the MCH Needs assessment

Child Health Intake Form (CHIF) Database

- CHIF Office Hours- will continue to be the 4th Wednesday of the month at 11am.
 - Next meeting- January 22nd
- CHIF orientation and guidance materials to be sent out with the manual update.
- If you run into any issues with the MFT submit tickets via [survey monkey](#).
- If you cannot access the survey monkey, please contact Amanda.
- If you run into any issues, please email Amanda Simon at amanda.simon@doh.wa.gov.

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

Washington Statewide Leadership Initiative (WSLI) and DOH Family Engagement

- Attended post-election AMCHP Board of Directors meeting as a Family Representative, 2024-2027.
- Served as the vice chair for the AMCHP Family Leadership Education and Development (LEAD) Committee.
 - Co-hosted and presented two café sessions on Highlighting Family Leadership within Title V: measuring what matters and the benefits of partnership.
 - Collaborating with National Blueprint Consortium partners to promote Blueprint knowledge and work to family leaders.
 - Planned for plenary presentation at the Title V Partnership Meeting in October.
 - Co-presented a plenary presentation at the 2025 AMCHP Conference in March.
- Supported revision and additions to the Care Coordination Toolkit.
- Ensured subrecipient contracts were amended to include federal fiscal year 2025. Executed on time.
- Attended State Title V Site Visit Review.
- Provided leadership for the CYSHCN Family Advisory Council (FAC).
 - Co-facilitated the September FAC meeting. Meeting was focused on the overall and CYSHCN-specific results of the MCH 5-year Needs Assessment and prioritization of major themes.
 - Recruited and oriented a family leader from the FAC to join the ongoing WA Blueprint for CYSHCN team.
 - Initiated review of notes of FAC meetings in 2023, looking for major themes as part of a report project.
- Led an internal Community of Practice focused on family engagement and using the FESAT.
 - Provided leadership to partner programs on using the FESAT to assess their programs' family engagement efforts for 2024.
 - Led CYSHCN team in using the FESAT to assess their collective family engagement efforts for 2024.

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

- Youth eating disorder guide created in partnership with Youth Advisory Council (YAC) nutrition subcommittee, check [Teen Health Hub WA | Washington State Department of Health](#) soon.
- Basecamp group for educators who teach cooking classes to youth with IDD has been created, please email Linda to be added: Linda.Ramirez@doh.wa.gov
- Based on a CYSHCN listening session feedback, we developed a simple, 1-page guide (English/Spanish) for pediatric facilities to help families identify warning signs and seek help quickly. Raising awareness can prevent delays in diagnosis and make sure children with T1D get the care they need when it is most effective. Please share or display these 1-pagers in your organizations and offices:
 - [Type 1 Diabetes Factsheet English](#)
 - [Type 1 Diabetes Factsheet \(Spanish\)](#)

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

Early Childhood and Communication Updates

- New quarterly GovDelivery CYSHCN Communication Network newsletter! Sign up here: [Washington State Department of Health \(govdelivery.com\)](http://WashingtonStateDepartmentofHealth.govdelivery.com)
- Reminder CYSHCN Orientation is scheduled for February 3rd

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

Essentials for Childhood (EFC)

For more information, contact Stacy Harris at Stacy.Harris@doh.wa.gov

Universal Developmental Screening (UDS)

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

MCH LHJ Contracts Updates

For more information, please contact Mary Dussol at 360-236-3781 or mary.dussol@doh.wa.gov.

Guest Presentations

OSPI (RNs/Special Ed/Early Childhood/Special Ed)

Annie Hazel and Ryan Guzman

OSPI School Health Services:

Key program components:

- Guidelines for school health services & Home Hospital
- Consultation, technical assistance, and Professional development
- Home Hospital Program
- Special Education
- Data collection and identification of trends in student health needs
- Partnerships with School Nurse Corps, public health, and more...
- School Nurse Advisory & School Nurse Connects – facilitated connections between school health and Department of Health

Guideline Revisions:

- **2021**
 - **Guidelines for Care of Students with Anaphylaxis**
- **2022**
 - **Guidelines for Medication Administration in Schools**
 - **Opioid-related Overdose Policy Guidelines & Training in The School Setting**
 - **Home/Hospital Services Guidelines**
- **2024**
 - **Guidelines for Care of Students with Diabetes**
 - **Infectious Disease Control Guide for School Staff**
 - ***Opioid-related Overdose Policy Guidelines & Training in The School Setting***

Guideline Updates – in Process:

- Opioid Overdose Reversal Policy & Training Guidelines
- How to Respond - Illness & Injury*
- Anaphylaxis - adding standing order
- Epilepsy and Seizures – School Nurse Corps
 - o *Collaboration with Department of Health

Current Project:

AED Access Grants

- 40 \$3000 grants for schools to ensure access to AEDs
- Application Deadline January 30, 2025
- Cardiac Emergency Response Plans Webinar Dec. 10, 2024
- Ongoing Collaboration with AHA and Project Adam

School Medicaid Billing:

[Link to report](#)

Feedback Session for parents and students

Wednesday February 26

4-5:30pm

[Webinar Registration - Zoom](#)

Goals:

- Behavioral Health services
- Nursing services
- OT/PT/SLP
 - Psychologists
 - BCBAs
- Simplify/streamline process

[School-based services feedback sessions 2024](#)

Questions & Answers:

Q; What are the 3 of 4 main health conditions OSPI deal with?

A: Anaphylaxis, Asthma, Diabetes, and seizures and epilepsy

Q: Were 48 does of naloxone were given at schools in 2023?

A: Yes, we are seeing overdoses in school

Q: Is there precedence elsewhere for behavioral health services administered in schools to be regularly reimbursed by Medicaid?

A: Yes, looking at a couple of states like Michigan and New Mexico that have implemented these expansions of Medicaid reimbursement

Key Considerations in Special Education; PreK-8: Ryan Guzman

The research has shown that over 90% of students with disabilities can be successful with grade level content in general education settings, with the right supports. And that offering flexible learning and supports benefits ALL learners – with and without disabilities.

Washington State's Journey Toward Inclusion:

In 2018, Washington state ranked 44th out of 50 states for K-12 inclusive practices¹.

To support more inclusive schools, the State Legislature funded a multi-year, statewide initiative to support professional development for inclusionary practices.

By 2023, year five of this initiative, schools in Washington state reported a **9-point** increase in inclusive practices statewide for K-12 and a **7-point** increase for Pre-K².

This means that, since 2018, over **22,000** students with disabilities across Washington state have shifted into the highest rates of inclusion!

The Equity Imperative:

- Barriers to equity for students with disabilities:

- Low expectations.
- Disproportionate identification, segregation & discipline for students of color.
- Lack of access and opportunity to core instruction from content experts.
- School schedules contribute to removals from core instruction in general education.
- Teacher and staff shortages.
- Training needs for educators & school staff.
- Staffing models that reinforce segregation.

What is a Regular Early Childhood Program?

- [WAC 392-172A-01152](#) **Regular early childhood program**
- Regular early childhood program means a program that includes at least fifty percent nondisabled children (i.e., children who do not have an individualized education program (IEP)).
- Programs may include, but are not limited to, the following: Head Start; early childhood education and assistance program (ECEAP); kindergarten; transitional kindergarten; preschool classes offered to an eligible prekindergarten population by the public school system; private kindergartens or preschools; group child development centers; or childcare.

What is the Least Restrictive Environment(LRE)?

- [WAC 392-172A-02050](#) **Least restrictive environment.**
- Subject to the exceptions for students in adult correctional facilities, **school districts shall ensure that the provision of services to each student eligible for special education services, including preschool students and students in public or private institutions or other care facilities, shall be provided:**
- (1) To the maximum extent appropriate in the general education environment with students who are nondisabled; and
- (2) Special classes, separate schooling or other removal of students eligible for special education services from the general educational environment occurs only if the nature or severity of the disability is such that education in general education classes with the use of supplementary aids and services cannot be achieved satisfactorily.
- (4) For children ages three to five, a general education environment is a regular early childhood program as defined in WAC 392-172A-01152.
- (3) The public agency responsible for providing FAPE to a preschool child with a disability must ensure that FAPE is provided in the least restrictive environment where the child's unique needs (as described in the child's IEP) can be met, regardless of whether the local education agency operates public preschool programs for children without disabilities.
- Least restrictive environment must be determined based on each individual child's needs and should not automatically be developmental preschool

What is a Free and Appropriate Public Education:

Under [WAC 392-172A-02000](#) **Students' rights to a free appropriate public education (FAPE)** (1) Each school district and residential or day schools operated under chapters 28A.190 and 72.40 RCW **shall provide every student who is eligible for special education between the age of three and twenty-one years, a free appropriate public education program (FAPE)...**

The right to special education for eligible students starts on their third birthday with an IEP in effect by that date. If an eligible student's third birthday occurs during the summer, the student's IEP team shall determine the date when services under the individualized education program will begin

The right to a FAPE includes special education services for students who have been suspended or expelled from school. A FAPE is also available to any student determined eligible for special education services even though the student has not failed or been retained in a course or grade and is advancing from grade to grade.

The Who-What-Where of Specially Designed Instruction & Special Education:

The Who:

WAC 392-172A-02090 Personnel qualifications.

- (i) Special education and related services must be provided by appropriately qualified staff. **Other staff including general education teachers and paraeducators may assist in the provision of special education and related services, provided that the instruction is designed and supervised by special education certificated staff (or early childhood special education certificated staff, deaf education certificated staff, deaf education with American sign language proficiency certificated staff, teacher of the visually impaired certificated staff), or for related services by a certificated educational staff associate.** Student progress must be monitored and evaluated by special education certificated staff or for related services, a certificated educational staff associate.

General Education staff can't do it on their own.

- The SDI must be designed and supervised by a certificated special education teacher and the students' progress must be monitored and evaluated by a certified special ed teacher. General Education teachers can be the providers of SDI and can collect data, as could a paraprofessional, to assist the special education teacher in monitoring and evaluating progress.

The Where:

- LRE is an individual decision.
- Full inclusion PreK can include a variety of supports.
- Full inclusion is not a place it is a practice of collected resources and supports to meet the individual needs of the child.
- WAC 392-172A-02055 Continuum of alternative placement can look like: 1/2-day or full day program offerings, different program locations, dual enrollment in ECEAP and DD PreK programs.

The What:

All students, regardless of program type, must be offered the support needed to meet their unique needs identified on the IEP, as was determined by the IEP team.

- The General Education staff should be teaching all students in the program and provide the accommodations and modifications identified on the IEP.
- It will be an IEP team decision if the General Education staff are in fact the providers of the SDI, as this will depend on the goals/skills of focus (e.g. adaptive skills – follow 1-2 step directions, social emotional – take and wait turns in large group).
- The role of the special ed teacher is not always to give direct instruction. Rather it might be to offer supplementary supports to the General Education teacher in the General Education settings.
- The IEP team, with administration, and program and district policies & procedures for special education, will provide a framework for IEP implementation when creating a student's IEP (program).

Inclusion in Early Childhood Programs:

Young children with disabilities must be given access to the early childhood programs, services, and experiences that children without disabilities have within a State or local community.

Specifically, high-quality inclusive early childhood programs are ones that:

- **Include children with disabilities in early childhood programs they would participate in if they did not have a disability, so they can learn together with their peers without disabilities;**
- Provide high-quality teaching and learning environments that support children’s development and allow all children to meet high expectations;
- Intentionally promote children’s participation in all learning and social activities, facilitated by individualized accommodations and differentiated interventions and instruction;
- Use high-quality, evidence-based services and supports that are developmentally appropriate, culturally and linguistically responsive, and that foster children’s—
 - acquisition and use of knowledge and skills,
 - use of appropriate behaviors to meet their needs,
 - positive social emotional skills, including friendships with peers, and
 - sense of belonging;
- **Provide services and supports to children with disabilities in early childhood programs with peers without disabilities, and within daily routines and learning and social activities;**
- Recognize families as collaborative partners, experts, and engaged decision-makers in their children’s lives and value **and treat children with disabilities and their families with respect;** and
- Ensure supports, such as screening and identification processes, early childhood program and school partnerships, access to and use of data, **and PD are in place to enable early childhood programs and providers to successfully include children with disabilities and their families.**

Essential Components of the SSIP:

Currently, Washington’s State Identified Measurable Result (SiMR) is designed to increase the social emotional learning (SEL) performance rates of entering kindergartners with disabilities across nine Educational Service District (ESD) and 27 local districts.

All local school districts recruited into the SSIP Implementation Project are contractors or subcontractors with the DCYF Early Childhood Education and Assistance Program (ECEAP), a state-funded preschool program; Head Start, a federally-funded preschool program; or a locally-funded community preschool program, are often licensed childcare facility, and enroll children between the ages of 3 and 5 years, with and without disabilities, who have met specific enrollment criteria.

Efforts are being made to assess and monitor existing supports for Tribal children with disabilities enrolled in existing early childhood programs and local districts and Bureau of Indian Education (BIE) schools.

This represents a sample of 27 local districts from ESD regions across the state, hosting children with disabilities enrolled in preschool (PreK) programs between the ages of 3-5 years with Individualized Education Programs (IEPs).

Elevating Community & Family Partnerships:

- Community Inclusion Project
 - Build a Community Charter
 - Target Audiences: Military families, Tribal Collaborations, Multicultural Families and language access
- Tribal Consultation

- Swan Innovations
- Office of Native Education
- Expanding partnerships through healing

- P-21 Systemic Equity Review with NCSI

Co-construct a systemic equity review process in partnership with the Washington state special education team, facilitate the team’s use of this process, and generate recommendations based on the outcomes of the review that support the development and adoption of state-level equity-driven beliefs, policies, procedures, and practices.

- Build a statewide MOU for the implementation of IDEA, Part B
 - In collaboration with Head Start, ECEAP, Child Care
- Development of Local MOUs
 - Part C, EI with Local Districts
 - Part B, 619, with Local Districts, State and Federal PreK, Child Care, etc.

- [Inclusionary Practices Professional Development Project | OSPI](#)

[Myths & Facts](#)- ECSE Edition: Use this document in its entirety or one myth as a time to better understand what implementation of inclusion look and feels like as there is no roadmap or ‘one size fits all’ process to achieve inclusive education.

Question and Answers:

Q: How lack of funding is impacting the services that students are actually receiving vs. what we know they need due to staffing and funding issues?

A: Staff recruitment and retention are a priority for our agency leadership. We have sought funding for a recruiting and retaining special education teachers through effective teacher residencies in the past.

Washington SNAP-Ed and Inclusive Nutrition

Tara McGinty, CHES, Jen Moss, RD

SNAP-Ed Mission:

The goal of SNAP-Ed is to make it easier for people who are eligible for SNAP/Basic Food to eat healthy and be physically active.

SNAP-Ed supports its mission through:

- Nutrition education
- Social marketing
- Policy, systems, and environmental strategies

SNAP-Ed Location and Composition

- Around 60 Providers
- Reach over 1.5 million people

SNAP-Ed Eligibility:

Individual

- SNAP (Basic Food) Participants
- Qualifying for SNAP, Medicaid, WIC or other means-tested programs

Community

- 50% or greater meet eligibility requirements
 - Free-Reduced Price Lunch
 - Census Tract
 - Food Banks/Pantries

Nutrition and Physical Activity Education:

252 class series reached 4,775 individuals

(92% youth)

Direct Education includes class series using approved curricula.

- Schools, housing, or community spaces

Indirect Education are activities and materials that support education.

- Food tastings and demos
- Flyers and handouts
- One-time events
- Tabling

Policy, Systems, and Environment (PSE):

329 activities reached an estimated

1,393,907 individuals

- **Policy, Systems, and Environmental (PSE)** change interventions address socioeconomic factors making the healthy options more accessible, easier, and the default.
- Policies and staff training
- Space layout and design
- Community gardens
- Train-the-trainer
- Build environment

Social Marketing:

A campaign for farmers market nutrition programs resulted in over 50 million impressions!

Social Marketing combines commercial marketing methods with public health approaches to achieve significant, large-scale public benefits.

- Banners and signage
- Videos
- Social Media
- Advertisements

Inclusive Nutrition Initiative: *A Partnership with Special Olympics*

Inclusive Nutrition Initiative (INI):

WHO:

- Special Olympics International (SOI)
- Nine state and tribal delegations from SNAP-Ed and Diabetes Prevention Programs
- SOI convened the INI to identify accessibility challenges, share best practices, and make commitments to help meet White House Conference goals and objectives.

Year 1 – October 2023, D.C.:

- Strengthened relationships with WA programs and external partners.
- Peer learning and networking with health messengers
- Developed 7 commitments to increase accessibility in WA SNAP-Ed

2023 Commitments:

Resources and Training

- Inclusive nutrition resource page
- Assess provider skill and interest
- Provide adaptive cooking toolkits

Partnerships and Collaboration

- Connect with Administration for Community Living-funded programs
- Establish Washington State Inclusive Nutrition Initiative
 - DOH: CYSCHN, Health Equity Zones, DPP, Evidence-based programs, WIC
 - DSHS: SNAP-Ed
 - External Partners: Special Olympics Washington

Incorporation into Statewide Systems for Equity and Inclusion

- Curriculum Rubric
- Anti-Racism and Equity Strategic Plan

Year 2 – October 2024, D.C.:

- Explored options for workgroups and broadening reach
- Reported on progress toward previous commitments
- Made 7 additional commitments to increase accessibility in WA SNAP-Ed

2024 Commitments:

Resources and Training

- Universal Design training for providers and leadership

Partnerships and

Collaboration

- WA Inclusive Nutrition Initiative meeting quarterly

- 2 new partnerships with organizations serving people with IDD
- Participate in 2025 Community Summit with DDA

Advisory Input and Compensation

- Include people with lived experience in program planning, training, and materials
- Provide compensation for people with lived experience that serve in an advisory capacity.

Resources:

- [Washington SNAP-Ed Provider Site](#)
- Washington SNAP-Ed [Provider Map](#)
- [Inclusive Nutrition Initiative Resources | Washington State SNAP-Ed Providers | Washington State University](#)
- [Empowering Culinary Exploration: Tips for Teaching Cooking Skills to Youth with Disabilities](#) course developed by the DOH Children and Youth with Special Healthcare Needs Program.

Questions & Answers:

Q: If the organization serves the population you just mentioned, can I refer them to SNAP-Ed? If so, what is a good contact number/email?

A: Please reach out to Tara with those questions! Tara.mcginity@dshs.wa.gov.

Parent Perspective

Jill Walsh

2015: At 2 ½ years old was diagnose with Autism. Services/Programs: Birth to 3, came to the house. Much support, guidance, is needed in the safety of home.

2015-2018: 3-5 years old;

Developmental Preschool: Services/Programs; Individualized Education Plan (IEP), School Speech Therapy, South Sound Parent to Parent: Play group meet ups, organized events-no need to worry about meltdowns, sensory-friendly events (plays, orchestras)

2018-2019: 6 years old

Mainstream Kindergarten: Services/Programs: IEP,SSP2P, Teacher Influence, School Speech Therapy/Social Skills, Accessible Performances, Sensory-friendly hours, Sensory Guides

- Sensory Friendly Performances: Televisions are available outside the show in case you need to leave the theatre at any point.
- **Social Narratives**, Character, Scene Breakdown and Apps for the event made available online prior to the performance

Social Narrative/Stories: Haircut Example

2019-2022: 7-9 years old

Mainstream First, Second & Third Grade- Including the COVID Years

Services/Programs: *IEP, SSP2P, Speech/Social Skills*

Thurston County Inclusion (TCI) – Play Dates, Organized events

Additional Organizations Offering Sensory Friendly Hours/Supports

2022-2023: 10 years old

Mainstream Fourth Grade

Services/Programs:

IEP, SSP2P, TCI, Speech/Social Skills

1:1 Para-educator

Lessons:

Testing Accommodations

Teacher Communication

Extra-Curricular Participation

(Prohibited) Para-educator/parent communication

2023-2024: 11 years old

Mainstream Fifth Grade

Services/Programs:

IEP, SSP2P, TCI, Speech/Social Skills

1:1 Para-educator

Lessons:

Test scores affect highly capable enrollment/eligibility

Teacher Influence

Para-educator/knowledge of student needs

Application to Highly Capable Program

2024-Present: 12 years old

Sixth Grade-Accelerated Math & Science

Services/Programs:

IEP, SSP2P, TCI,

1:1 Para-educator

Lessons:

“The kid on paper is not the kid we have”

Adjusting IEP goals

Closing Thoughts

- You don't have to understand something for it to be true for someone else.
- Book recommendations – by autistic authors.

- A Kind of Spark by Elle McNicoll

- The behavior – “it’s not about what it’s about”

Contact Info:

Jill Walsh

jillwalsh2013@gmail.com

BreatheWell Inspiration-Medically Complex/Trach/ Vent Education

Leslie Elder, MSN, RN

Seattle Children’s Hospital—1990-2023

National Corporate Clinical Specialist

Aveanna 2015-2017

- Nurse Tech
- Staff Nurse
- Charge Nurse
- Pulmonary Case Management/Discharge Coordination
- Inpatient Case Manager—Pulmonary, Craniofacial, Neurosurgery, E.D., Medically Complex Service, Oto..

Co-Creator: Seattle Children’s Trach Safe Program 2013→

- Airway evaluation prior to discharge—> emergency airway management plan
- Trach Safe Emergency Airway Management Class
- Near Miss data collection
- Medic 1 education

New Models of Care 2022→—Statewide workgroup, develop new caregiver type for pediatric complex care at home

BreatheWell Inspiration—2023→

- Medically complex/ trach/ vent education

MISSION → HELPING PEOPLE HELP PEOPLE

- Access to high quality, expert

education—Federal Way, WA

- Lecture/practice
- Simulation

- routine and emergency airway care
- assisted ventilation
- medically complex medication regimens
- enteral feeding

Simulation Pods

[BACK TO TOP](#)

Classes

TRAINING MATTERS...

- In pediatric home care, the lack of expert nursing contributes to a higher occurrence of life-threatening situations (Reiter, Pernath, Pagal, Hiedi, Hoffman, Schoen, & Nicolai, 2012)
- Video/online/self-report alone forgoes the ability for return demonstration; nurses do not receive ongoing training or clinical updates on this specialized training; CPR training does not meet the needs of trach/vent children at home; a lack of vigilance at home leads to preventable deaths

(Boroughs & Dougherty, 2012).

- Inadequate pediatric home care increases the risk of readmission (Kun, Edwards, Davidson Ward & Keens, 2012)
- Children die at home from avoidable causes of death (Edwards, Kun & Keens, 2010)
- Children are not small adults and they're at high risk for problems at home:
 - Smaller airways, natural and artificial=> higher risk for obstruction
 - Less effective cough clearance
 - Decreased diaphragmatic efficiency
 - Lower nutritional reserve

(Peterson-Carmichael & Cheifetz, 2012)

- Comorbidities with complex care needs

(Roy Elias, Murphy, et al., 2012)

- Parents want home nurses who can “think on their feet” and quickly respond to emergencies without hesitancy (Mendes, 2013)
- Parental hopelessness is fueled by pediatric home nurse/caregiver incompetence (Boroughs & Dougherty, 2009)

WE CAN DO BETTER

WE NEED TO FILL UP THE CAREGIVER POOL WITH PREPARED CAREGIVERS

Lungs and airways

When It All Goes Wrong:

- Air cannot get in
- Air cannot get out
- Diffusion isn't working well
- Illness
- Broken/missing equipment or supplies
- Complacency

...You need muscle memory

What does distress look like:

- Increased HR/RR, Decreased SATs (maybe)
- DIAPHORESIS (SWEATING)→ NEUROMUSCULAR WEAKNESS SIGN OF DISTRESS
- COUGHING

- ANXIETY
- LETHARGY/TIRED/ACHES

Cough Reflex:

You must know this as a caregiver to save lives

IF YOU CAN'T TAKE A BIG BREATH, YOU CAN'T COUGH AT ALL OR NOT WELL

- ✓ Low tone-- conditions of weakness--debilitated, neuromuscular diseases
- ✓ High tone--chest wall contraction hampered by stiff muscles at baseline
- ✓ Trach tube in place--can obstruct movement of secretions, minimize big breath
- ✓ Diaphragm abnormalities
- ✓ Quadriplegia (no impulse via the phrenic nerve to diaphragm, injury at/above the 4th cervical vertebrae)
- ✓ Craniofacial abnormalities/obstructed upper airway--can't close the glottis
- ✓ Abnormal vocal cord motion--can't close for back pressure to build
- ✓ Brain does not trigger the cough reflex--abnormal brain function

Resuscitator Bag:

Peep Valve: Resuscitator bags can be fitted with a valve which helps to maintain the positive end-expiratory pressure required by the patient.

Pop off valve/override: Feel the air with inflation

Manometer: measures the pressure of inflation

Medication overview Rx

Order of medications

G-Tube at your station:

Stoma Complications

Farrel bags/venting

Obstructive lung disease/Interventions

Caregiver Education:

PLEASE JOIN IN TRYING TO IMPROVE THE LIVES OF THESE CHILDREN AND FAMILIES AT HOME

QUALITY EDUCATION PLAYS A SIGNIFICANT AND POSITIVE ROLE IN THIS TYPE OF CARE AT HOME

QUALITY EDUCATION IS READY--JUST DOWN THE ROAD

SEE ONE, DO ONE, TEACH ONE HAS TURNED INTO SEE ONE, DO ONE, SIMULATE MANY

Questions and Answers:

Q: Would you accept financial assistance from agencies for a family?

A: Yes

Q: Do you ever travel to bring the class to other locations?

A: Yes, but office is location in Federal Way, WA

Q: Do you have a class on NG tubes?

A:Yes

Q: Are NICUs aware of your service?

A: Most big NICUs are aware in Washington State

Q: Are families able to learn together under one sign up or per person?

A: BreatheWell could work something out

CSHCN Coordinator Updates by County

Gathered from counties and shared on a quarterly basis.

Asotin County Health District

Lora Gittins, CYSHCN Coordinator

Clark County Public Health District

Jan Schmalenberger, CYSHCN Coordinator

February 1st will be the first CYSHCN Dental Day. Clark College Dental Hygiene School board has agreed to designate 2 hours at the end of Children's Dental Day to serve children with specialized needs. We are hoping this will have a positive impact on the community and continue annually. This effort is a collaboration between ABCD Coordinator, CYSHCN Community Health Specialist, Clark College Dental Hygienist director, pediatric dental champion, Dr. Hsu, and volunteer dentist, and our local NDC in providing OT support.

Grays Harbor County Public Health

Stefani Joesten, CYSHCN Coordinator

Grant County Health District

Janette Garza, CYSHCN Coordinator

Island County Public Health

Megan Works, CYSHCN Coordinator

Jefferson County Public Health

Cynde Marx, CYSHCN Coordinator

Pacific County Children and Youth with Special Health Care Needs

Brianne Cline, CYSHCN Coordinator

Translated intake and demographics forms to Spanish to better serve Pacific County.

San Juan County

Kristen Rezabek, MS, RDN, CD, CDE

Spokane Regional Health District

Kristin Lester, CYSHCN Coordinator

Thurston County Public Health and Social Services

Bonnie Peterson, CYSHCN Coordinator

I saw a greater need for families needing more connections to local services and resources.

Yakima County- Children's Village

Tracie Hoppis, CYSHCN Coordinator

Continued work with Blueprint project; hosted Yakima County Care Coordinators meeting with presentation from ESD 105 Behavioral Support Program; Coordinated Central Washington Interagency Transition Network meeting agenda with presentations on Person Centered Planning and County Developmental Disabilities program transition services. Convened multidisciplinary staffing meetings improved coordination of care for children and families.

Neurodevelopmental Center (NDC) Updates

Check out the NDC StoryMap: [Neurodevelopmental Centers of Excellence of Washington](#)

Peace Health Children's Therapy - Whatcom County

Kris Gaggero, Clinic Manager

Mary Bridge Children's Therapy Services

Kari Tanta, Manager

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

Kinderling

Kathy Fortne, Director of Operations

www.kinderling.org

HOLLY RIDGE

Alicia Skelly, Infant Toddler Program Director

Holly Ridge has been serving on average 490 children each month this quarter. We have been able to increase our staffing - we hired a Speech Language Pathologist, a Special Educator and a Compliance and Insurance Coordinator. Our referrals continue to come in steadily.

We have a pilot program that started in October with a community agency called Kitsap Community Resources (KCR) called Growing Together. The program has families served by Holly Ridge and KCR come together Monday through Friday for two hours for an inclusive socialization experience - there is free play, outside play, snack time and circle time activities. To date children and families are enjoying the opportunity.

Holly Ridge continues to offer opportunities to Family Practice physicians from a local residency program - Northwest Family Medicine Residency Program in Bremerton, to come to our agency to learn about Early Support Services, how to make referrals and observe evaluations. Holly Ridge also continues to partner with the Olympic college's nursing program. nursing students can observe our case conference meeting and ask questions afterwards to learn about the services we provide.

We are looking forward to a great year in 2025!

Children's Therapy Center

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

Health Plan Updates

Wellpoint

Derek Steele, Manager, Case Management

No updates at this time.

Community Health Plan of Washington (CHPW)

www.chpw.org

No updates at this time.

Coordinated Care

Sherry Bennatts, Senior Manager, Case Management

www.coordinatedcarehealth.com

Molina Healthcare of Washington

Kelly Anderson, Program Director, Healthcare Services

www.molinahealthcare.com

No updates at this time.

UnitedHealthcare

Cassie Milson, Private Duty Nursing Case Manager

www.uhc.com

[Coverage Area Includes: 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

Washington State Parent to Parent, with 50+ parent coordinators working in community-based programs, provides peer and family support services in all 39 Washington Counties. During this quarter's monthly Network meetings, we had the following presentations: Legislative Advocacy with Cathy Murahashi, The Arc of Washington; Cass Griffin, Northwest Augmentative Communication Society and Pam Blanton, Partners4Housing.

We finished the Dan Thompson Community Grant which enhanced multicultural programming across many programs and welcomed a small increase in funding from DDA.

Washington State Medical Home Partnerships Project for CYSHCN

Kate Orville

www.medicalhome.org

- 1) Autism Center of Excellence Training Sept 29th- 82 COE eligible of which 38 are now COE certified and 50 attending partners. Feb 2, 2024, COE training has 52 COE eligible clinicians registered and 27 partners (MCOs, CSHCN Coordinators, LMHC, SLPs etc.) Register: <https://redcap.link/Feb2024COE>
- 2) With funding from the DOH CYSHCN program, we are able to offer autism evaluation tools and training to community COEs and EI (SLP/OT etc.) partners. a) School Medical Autism Review Team (SMART) members from Jefferson, Skagit, King, Benton-Franklin and Thurston Counties participated in

[Back to top](#)

ADOS-2 training in September and October; SMART members including those from Yakima and Spokane will be doing ADOS-2 training in March. b) The Screening Tool for Autism in Toddlers and Young Children (STAT) is a highly regarded, family friendly focused screening tool. We are collaborating with Wendy Stone, a PhD co-developer of the tool to provide training and tool kits to interested COEs and EI clinicians/teachers across WA. We currently have 4 all day virtual training days set up with COEs and EI in different cohorts, 20 slots per training. The EI cohorts are filled (Jan 16 and April 3) The COE cohorts are filling fast (Feb 9 and April 17) Participants for the first two cohorts come from 20 counties across WA. We expect to be able to offer additional training later this year. 3) WA INCLUDE Collaborative ECHOs- MHPP staff participated as faculty for the ECHO Autism Orange cohort for new autism diagnosticians and the ECHO Intellectual/Developmental Disability (I/DD) Resources and Resource Navigation. LHJ CYSHCN Coordinators and MCO staff make up big, knowledgeable groups of the Resources Navigation cohort (this ECHO will start again in April). There is also an I/DD Systems Wraparound ECHO with leaders from different systems (HCA, DDA, etc.) Learning about and problem solving cases where I/DD and mental health are both heavily involved and an I/DD psychiatric care ECHO. 2024 sessions are available to enroll in now at <https://wainclude.org/> (note you need to first sign up for the website, then enroll in your ECHO(s)). 4) MHPP colleague Sophie Lu, ARNP, and her husband Mark are the new parents of baby girl Hallie Huynh Maleng was born on 12/1/23. Hallie, Sophie, and Mark are doing well and enjoying their time together snuggling and reading. Sophie is on maternity leave until July 2024.

University of Washington CSHCN Nutrition Project at CHDD

Mari Mazon, MS, RDN, CD

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

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

We held our 27th Nutrition Network Training in December 2023 and welcomed 18 registered dietitian nutritionists to the CYSHCN Nutrition Network. Our newest members serve Adams, Thurston, Mason, Grays Harbor, Kitsap, King, Pierce, Snohomish, Skagit, Chelan, Douglas, Benton, Franklin, Walla Walla, Stevens, Pend Oreille, and Ferry Counties. The Nutrition Network now has over 200 active members.

Washington State Fathers Network (WSFN)

Louis Mendoza

www.fathersnetwork.org

Family to Family Health Information Center (F2FHIC)

Jill McCormick

www.familyvoicesofwashington.com

No updates at this time.

Open Doors for Multicultural Families

Hodan Mohamad

www.multiculturalfamilies.org

No updates at this time.

Washington Autism Alliance & Advocacy (WAAA)

Arzu Forough

www.washingtonautismadvocacy.org

No updates at this time.

Office of Superintendent of Public Instruction (OSPI)

Nicole Klein, Health Services Program Supervisor

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

Seattle Children's Hospital

Paula Holmes

www.seattlechildrens.org

No updates at this time.

Lifespan Respite Washington (LRW)

Linda Porter

www.lifespanrespitewa.org

No updates at this time.

WithinReach

Chris Gray

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

DSHS, Developmental Disabilities Administration (DDA), Waiver Unit

Kari Freer

No updates at this time.

DSHS / DDA, Medically Intensive Children’s Program

Doris Barret

DSHS, Fostering Well-Being Care Coordination Unit (FWB CCU)

Autumn Wade and Amanda McCleskey

DSHS / ALISA, Kinship Care and Lifespan Respite

Rosalyn Alber

www.dshs.wa.gov/kinshipcare

No updates at this time.

DOH Screening and Genetics Unit

Nini Shridhar

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

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

April 10, 2025

Virtual Meeting