



# Children & Youth with Special Health Care Needs

[www.doh.wa.gov/cyshcn](http://www.doh.wa.gov/cyshcn)

## COMMUNICATION NETWORK MEETING

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

[www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/ChildrenwithSpecialHealthCareNeeds.aspx](http://www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/ChildrenwithSpecialHealthCareNeeds.aspx)

## General Updates

[MCHBG Needs Assessment Discovery Survey](#) is out now – please share widely

The next Autism Center of Excellence (COE) training is Friday Feb 2, 2024- registration is through this page:

<https://medicalhome.org/event-home/autism-center-of-excellence-certification-trainings/>

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

## Child Health Intake Form (CHIF) Database

CHIF data will continue to be collected quarterly by spreadsheet as we've done since July 2022.

Please direct any questions about CHIF to the CHIF Inbox- [DOH-CHIF@doh.wa.gov](mailto:DOH-CHIF@doh.wa.gov).

Planning for the improved CHIF system is ongoing, and please be on the look for a Survey to assist us in our planning.

*For more information, contact Amanda Simon at [Amanda.Simon@doh.wa.gov](mailto:Amanda.Simon@doh.wa.gov)*

## CYSHCN Communication & Early Childhood

2024 CYSHCN meetings have been sent out, please reach out to Linda if you would like to be added to the meeting invite list.

Washington STEM's [2023 State of the Children statewide report](#) is out now in English and Spanish.

The DOH Strong Start program is looking for healthcare providers that regularly do developmental screenings to partner with them to enhance interoperability of electronic health records with Strong Start. Up to \$30,000 is available per participating healthcare practice for this project. Total funding available is \$60,000. Interest forms are due to Marilyn Dold at [marilyn.dold@doh.wa.gov](mailto:marilyn.dold@doh.wa.gov) by COB Thursday Jan 18, 2024.

Updated [Children and Youth with Special Health Care Needs Coordinators](#) contact list.

Updated [Managed Care Organization](#) contact list. Please note that Amerigroup has changed their name to Wellpoint.

*For more information, contact Linda Ramirez at [Linda.Ramirez@doh.wa.gov](mailto:Linda.Ramirez@doh.wa.gov)*

## Washington Statewide Leadership Initiative (WSLI) and DOH Family Engagement

UW and DOH Child Health team recently released [Data Analysis: Family Voices in Washington State](#) report.

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

Standing up Type 1 Diabetes family support through PAVE in partnership with Parent to Parent.

*For more WSLI or DOH Family Engagement information, contact Nikki Dyer at 360-236-3536 or [nikki.dyer@doh.wa.gov](mailto:nikki.dyer@doh.wa.gov).*

## **CYSHCN Program Nutrition Updates**

Understanding Eating Disorders in Adolescents: A Guide for Healthcare Providers is finalized. We would love to help sharing this document to providers.

Module for how to teach cooking skills to youth with disabilities will be finalized by February 2024

Consider joining the Type 1 Diabetes (T1D) workgroup if this is a population of interest, we meet monthly, the 4<sup>th</sup> Wednesday at 8AM

T1D Statewide Coordinator in partnership with PAVE/P2P will be in full swing supporting newly diagnosed T1D families in 2024 and Teen Connect virtual group continues.

*For more information, please contact Khimberly Schoenacker at 360-236-3573 or [khimberly.schoenacker@doh.wa.gov](mailto:khimberly.schoenacker@doh.wa.gov).*

## **CYSHCN Behavioral and Adolescent Health**

PMHCA-SAFES program services are up and running with SCH and Frontier Behavioral Health

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.

DOH funding two grants of up to \$30,000 for "The Youth Mental Health Access Community Project" focused on reducing barriers to mental health for BIPOC patients between the ages of 6-17. Learn more at DOHs WA Portal:

<https://bit.ly/46Faavo>

*For more information, contact Renee Tinder at [Renee.Tinder@doh.wa.gov](mailto:Renee.Tinder@doh.wa.gov)*

## **Essentials for Childhood (EFC)**

UW and DOH Child Health team recently released [Data Analysis: Family Voices in Washington State](#) report.

*For more information, contact or see [www.doh.wa.gov/efc](http://www.doh.wa.gov/efc).*

## **Universal Developmental Screening (UDS)**

The DOH Strong Start program is looking for healthcare providers that regularly do developmental screenings to partner with them to enhance interoperability of electronic health records with Strong Start. Up to \$30,000 is available per participating healthcare practice for this project. Total funding available is \$60,000. Interest forms are due to Marilyn Dold at [marilyn.dold@doh.wa.gov](mailto:marilyn.dold@doh.wa.gov) by COB Thursday Jan 18, 2024.

*For more information, contact Marilyn Dold at [Marilyn.dold@doh.wa.gov](mailto:Marilyn.dold@doh.wa.gov).*

## **MCH LHJ Contracts Updates**

[MCHBG Needs Assessment Discovery Survey](#) is out now – please share widely.

*For more information, please contact Mary Myhre at [Mary.Myhre@doh.wa.gov](mailto:Mary.Myhre@doh.wa.gov)*



## CYSHCN Communication Network Agenda

Time	Topic	Presenter
9:00-9:20	Welcome, Agenda, Program Updates	Renee Tinder
9:20-10:00	SSI Applications for Children	Ruth Daugherty, NW Access Fund
10:00-10:25	Youth Behavioral Health Navigator Program	Edward Michael, HCA Gina Cabiddu, Kid's Mental Health Pierce County Meghan Hopkins, DDA
10:25-10:35	<b>Break</b>	
10:35-10:55	Autism & Suicide/ Lived Experience	Zack Siddeek, ARC King County
10:55-11:55	DOH Discovery Survey Facilitated Discussion	Mary Myhre, DOH
11:55-12:00	Final Questions & Closing	Renee Tinder

## Guest Presentations

### SSI Applications for Children

Ruth Daugherty, Youth Program Manager, NW Access Fund

#### Agenda:

- Overview of Northwest Access Fund
- SSI Basics
- Definitions of disability (child & adult)
- Application process
- Next Steps

#### About Northwest Access Fund:

- Mission: We offer people with disabilities customized loans, financial coaching, and other resources to promote access to assistive technology, independence, financial resilience, and life opportunities.

- Serve all of Washington and Oregon; expanding into Idaho.
- All incomes, all ages, all disabilities
- 501©3 & Community Development Financial Institution (CDFI)

### NWAF Programs:

- Assistive Technology: Up to \$25,000, 5-year term; 5% interest
- Modified Vehicles: Up to \$65,000, 10-year term; 5%-9.25% interest
- Home modifications: Up to \$40,000, 10-year term; 5% interest
- Opportunity Loan: Up to \$10,000, 5-year term; 5% interest
- One-on-One Financial Coaching
  - Resources navigation
  - Credit building
  - Budgeting
- One -one-One Disability Benefits Planning
  - All coaches are certified benefits planners
- No fees for loans, and financial coaching is free

### Youth Program:

The Youth Program provides free education and support on financial basics and disability benefits for youth with disabilities ages 14-25 and their families as they transition to adulthood

#### How we can help:

Northwest Access Fund provides help to apply for disability benefits by providing information about the process, answering questions, and providing support and resources along the way. We cannot guarantee that an application will be approved, and denials can happen even when the disability is obvious and well documented. 60-70% of initial applications are denied each year. If an application is denied, we can refer to an attorney. We are not attorneys and cannot provide legal advice, and cannot help with appeals.

### SSI BASICS:

#### SSI-What is it?

- Supplemental Security Income (SSI) is a monthly payment for people with disabilities who have income and assets below specific limits and limited or no work history. The program is administered through the Social Security Administration.
- Please Note: SSI will be cover and not information related to Social Security Disability Insurance (SSDI)
  - The reason for this is that most youth are eligible for SSI rather than SSDI. Eligibility for SSDI as a child or young adult requires that at least one parent be retired, disabled, or deceased, and this is less common.

#### SSI- Who gets it?

- Eligibility:
  - Less than \$2,000 in resources
  - Low income or no income
  - Little or no work history
  - Meet the Social Security Administration’s definition of disability
- IMPORTANT: Age 18 and the end of deeming!

- Before age 18, parental income and resources are “deemed” to the child, but that ends at age 18 and parental income and resources are not considered any more. So, many youth are eligible for the first time at age 18 because only their personal income and resources are counted.
- You can begin the application up to 6 months before the youth’s 18th birthday.

### SSI- How much is it?

- The benefit rate changes each year due to cost of living adjustments.
- In 2024, the maximum amount is \$943/month.
- The benefit amount can be impacted by:
  - All types of income, including gifts
  - Living arrangements
  - Family size, including marriage

### SSI-What comes with it?

- With SSI comes eligibility for these programs:
  - Medicaid(!!!)
  - Food assistance (SNAP)
  - [Vocational Rehabilitation](#)
- Medicaid funds programs for in home and community supports for those that need them as well as providing medical coverage and prescriptions at no cost to the recipient. Other private insurances do not provide support for in home and community supports making Medicaid essential for those that need that support.
- DVR provides job training, job placement, and job coaching for people with disabilities

### SSI & Work

- It is possible to receive SSI and work!
- SSI has some work incentives, including a great one just for young adults
- The amount of SSI will decrease as earned income increases, but you will always end up with more money if you are able to work.

### Definitions of Disability and How to Meet Them

#### Definition of Disability-Child:

- The child must have a physical or mental condition(s) that very seriously limits his or her activities; and
- The condition(s) must have lasted, or be expected to last, at least 1 year or result in death.

#### Meeting the definition of disability: Impact of disability

- SSA maintains a [Listing of Impairments-Childhood Listing](#) online, which lists every eligible diagnosis for childhood disability
- Review the eligibility criteria for the applicant’s diagnosis
- Prepare a statement about how the child’s disability impacts their daily functioning. The application must demonstrate a severe impairment.
- Recommendation is to review the eligibility criteria for the applicant’s diagnosis before starting any paperwork. The purpose of the statement is to think through how the applicant’s diagnosis matches the eligibility criteria and the definition of disability, and how it impacts their daily functioning; put this in a narrative, and then use that to guide the application. Doing this on the front end prepares you to complete the paperwork and the interview.
- SSA will consider factors like:

- Ability to stand, walk, lift, carry, see, hear, and speak
- Understanding, remembering, carrying out simple instructions, judgement, responding to supervision, dealing with changes

### **Adult definition of disability:**

The social security administration defines disability as:

- The inability to engage in substantial gainful activity (SGA)
- Because of medically determinable physical or mental impairments(s)
- That has lasted or is expected to last for a continuous period of at least 12 months or is expected to result in death

Substantial Gainful Activity for 2023 means earning \$1470 or more each month. 2024 is now \$1550.

\*The adult definition is different from the childhood definition in that it is all focused around the ability to work.

### **Meeting the Definition of disability: Impact of disability**

- Adult benefits are based on ability to work, so be prepared to address how the disability impacts the applicant's ability to work

SSA looks at 4 areas of functioning for adults.

- Activities of daily living
- Social functioning
- Concentration, persistence, and pace
- Ability to adapt or manage oneself

Keep these areas of functioning in mind as you prepare a statement on the impact of the disability.

### **Meeting the Definition of Disability: Documentation**

- Collect medical records from the onset of the disability
- If the applicant is in school and has an IEP or 504, request records from the school.
- Medical diagnoses are more important than educational eligibility.

### **Tips: Impact of Disability**

- SA Needs to know what the applicant cannot do and what is hard for them. Talk about challenges and struggles, and what support is needed.
- Compare the applicant to a typically developing peer
- Think about the most challenging day in the last 6 months. What support was needed on that day? What were the challenges? Write your narrative based on that day.

### **Example:**

## 112.10 Autism spectrum disorder (see 112.00B8), for children age 3 to attainment of age 18), satisfied by A and B:

1. Medical documentation of both of the following:
  1. Qualitative deficits in verbal communication, nonverbal communication, and social interaction; and
  2. Significantly restricted, repetitive patterns of behavior, interests, or activities.

AND

2. Extreme limitation of one, or marked limitation of two, of the following areas of mental functioning (see 112.00F):
  1. Understand, remember, or apply information (see 112.00E1).
  2. Interact with others (see 112.00E2).
  3. Concentrate, persist, or maintain pace (see 112.00E3).
  4. Adapt or manage oneself (see 112.00E4).

### Application Process

#### What is Needed

- Identifying documents
  - SS number
  - Birth Certificate
- Medical Information
  - All doctors and specialist, past and present
  - Any assessments of functional level performed by a doctor or specialist.
  - Dates and outcomes of major treatments.
  - Dates of any co-occurring diagnoses.
- Names, addresses, and phone numbers for medical providers. If it's been a while since the applicant has been assessed, it may be helpful to ask for updated functional assessments from providers before starting the application.
- School records (Still in school or recent graduate)
  - IEP or 504, past and present
  - Psychological evaluation, past & present
- Proof of income
  - Adult application- youth's proof of income
  - Child application- parents' proof of income
- Proof of resources
  - Adult application- youth's bank statements
  - Child application- parents' bank statements
- Proof of living arrangements
  - Lease
  - Information about household costs
- SSA may accept these records from you, or they may say that they need to request them directly from the medical providers and schools. Even if they won't take them from you, you will need to have them to accurately answer questions on the Adult Disability Report and in the interview. You have a better chance of a successful application if you have these records from the beginning.

#### Child Application Process:

- Options:
  - Complete Child Disability Report online, then schedule the interview to complete the application
  - Request an appointment for an interview to complete the Child Disability Report & application

- Tip: Use a PDF or printout of the Child Disability Report as a worksheet to gather all your information, then enter it into the online Child Disability Report form.
- The Child application process starts with the Child Disability Report.
- We recommend completing the Child Disability Report online, and so does SSA. You can start it and come back to it with a re-entry code, and this lets you work at your own pace and make sure you have all the documentation that you need. Once you begin the application, you have 60 days to complete it.

#### The Child Disability Report:

- The Child Disability Report is the first step of the application and can be completed online. If you have already gathered your documentation and worked on a narrative about the impact of the disability, you should have all the information you need to complete this form.
- 14 pages, 10 sections
- Section 1: Information about the child
- Section 2: Contact information
- Section 3: Disability & impact on the child
- Section 4: Medical records
- Section 5: Medications & side effects
- Section 6: Tests
- Section 7: Additional information (other agencies/services)
- Section 8: Education
- Section 9: Work history (of the child)
- Section 10: Date & remarks

#### Adult Application Process:

- Options:
  - Start the [application online](#), then complete the interview
  - Request an appointment for an interview to complete the application
- Once an application is initiated, it must be completed within 60 days.

*We recommend starting the application online.*

- The adult application process starts with an online application rather than with the Disability Report, which is completed after the initial application.

#### Adult: The Online Application:

- Identification
  - Demographics
  - Basic disability questions
- General
  - Marriage and dependent information
  - Employment information
  - Eligibility for other benefits
  - Bank account information
- Remember, the adult application has an initial online application that the child application doesn't have. The reason for this is complicated and is essentially because this is also an application to determine eligibility for SSDI.
- Other benefits

- Information about other benefits
- Ability to work
- Disability payments
- Employment wage information
- Authorization for disclosure of medical information
- If the applicant can't complete the application in one sitting, they will receive a re-entry number to access it again.
- Some applicants can complete the iSSI application online. They'll still need to answer additional questions in the interview.
  - The iSSI is a shorter application with fewer questions. Not everyone can use it.

### Adult Disability Report:

- After completing the online application, complete the Adult Disability Report online
- Medical and educational records will be needed to complete this form
- *Tip: We recommend using [the fillable PDF](#) or a printed version of this form as a worksheet to gather information before completing the form online*
- The Adult Disability Report is similar to the Child Disability Report, but with more work-related questions. For both the Child and Adult Disability Report, the biggest piece is filling in medical history. This requires having access to medical records because you must know the dates of first, last, and next appointments, names, addresses, and phone numbers of providers, dates of testing, etc.

### Function Report:

- Describes how the disability limits activities
- Child- Third party version
- Adult- First person & third party versions
- *Tips: Describe struggles and challenges on worst day. Be honest and realistic. Be as detailed as possible. Compare the applicant to a typically developing peer as you think about what they can and cannot do.*
- There are multiple versions of the Function Report for different age groups. It's very important to fill out the Adult Disability Report and the Function report completely and thoroughly. Spend a lot of time and energy here. Tie it to the Listing of Impairments description of the applicant's disability. For adults, the 1<sup>st</sup> person version should be used if the applicant has a way to communicate and can respond to the questions; if not, just use 3<sup>rd</sup> party version. You can use both.

### Tips:

- Don't wait for SSA to gather records- applicant should begin requesting records ASAP
- Applicant should make a list of every medical provider they remember seeing and request records from each
- Applicant should contact their school and request every IEP they've had, along with any educational evaluations
- Medical diagnoses are more important than educational eligibilities. School records are helpful and important, but medical records have more weight. Social Security may accept medical and school records from you, or they may say that they have to request them directly from the providers and schools. Either way, it is best to have these records yourself while completing the forms and interview.
- Medical records > educational records
- Organize records chronologically
- **Keep copies of every document given to SSA. They will probably lose something, somewhere along the way**

### Child: Interview & Application

- Medical:
  - Medical records on hand to answer questions
  - Names, addresses, and phone number for all medical providers for at least the past year
  - Medications child is taking
- Educational:
  - Names, addresses, and phone numbers of schools attended for at least the past year
  - Names of teachers, speech/occupational/physical therapists, psychologists, school counselors
  - IEPs or 504s and evaluations

### The Interview:

- Disability and its impact
  - When the disability began
  - When the disability was diagnosed
  - Impact of the disability on child's activities
- Names, addresses, and phone numbers of anyone who helps care for the child
- Income and resources
  - Sources and amounts of income
  - Monthly expenses
  - Resources including properties, cars, bank accounts, cash, etc

### Adult: Interview & Application

- Medical Information & Impact of disability
- Income and resources
- Living arrangements
- Past and current employment
- **The Adult interview has some similarities, but employment rather than education will be a big focus, and the adult interview will talk extensively about living arrangements.**

### Income & Resources:

- SSI has a resource limit of \$2,000. If the applicant has \$2,000 or more in a bank account, they will be found ineligible for benefits
- Open an ABLÉ account to save without impacting eligibility for benefits!
- Applicant's countable earned income must be below \$943/month if they are paying for food and shelter, and below \$629/month if they are not paying for food and shelter

### Living Arrangements:

- Very important! Living arrangements can reduce the SSI check by one third.
- If the youth is living with family members and is not paying rent, we recommend setting up a rental agreement to avoid the one-third reduction.

### What to expect:

- A long wait!!!
- SSA website states that supplication may take 3-5 months, but it may take much longer
- Between 60-70% of initial applications are denied each year
- Approval may require multiple appeals and legal representation



- Disability Determination Services (DDS) will receive portions of the SSI application and will determine if the disability meets the medical standards.
- Applicant may hear from DDS by mail and/or by phone; make sure to respond quickly to all communication.

#### After approval:

- May take up to 3 months to get first payment
- May get a lump sum of “back pay,” which must be spent or saved in an ABLE account, trust, PASS, or a another excluded resource within 9 months of receiving it.
- Applicants have a right to appeal
- Legal representation for an appeal is recommended
- Northwest Access Fund does not provide support with appeals (you want a lawyer for that!)

#### Next Steps:

- Child:
  - Find Condition in listing of impairments
  - Gather medical records
  - Give medical providers [signed release](#) to share records with SSA
  - Gather educational records
  - Give schools [signed release](#) to share records with SSA
  - Ask teacher to complete [Teacher Questionnaire](#) Form
  - Complete the Child Disability Report
  - Complete the Function Report
  - Make copies of all documents
  - Schedule & complete interview
  - Submit Function Report & medical/educational records
- Adult:
  - Complete the online application
  - Complete the Adult Disability Report
  - Complete the Function Report
  - Make copies of all documents
  - Schedule & complete interview
  - Submit function Report, Adult Disability Report, Rental Agreement & medical/educational records

#### Need More Support?

##### What We Offer

- Free, one-on-one coaching sessions on basic financial concepts and/or disability benefits via phone or zoom
- We can work with youth and/or with families
- Schedule from the website: <https://www.nwaccessfund.org/youth/coaching/>
- Dolla\$ & Bill\$: A Financial Foundations Course for Youth with All Kinds of Disabilities
  - Small group
  - Online
  - Covers basics of money management and credit
  - <https://www.nwaccessfund.org/youth/course/>
- Monthly classes on SSI applications for children under 18 and 18 or older
- Register on the website: <https://www.nwaccessfund.org/youth/navigating-ssi/>

## Accessing Services:

- Eligibility:
  - Ages 14-25 and self-identify as having a disability; under age 18, parent or guardian should be involved in coaching with the youth.
  - Documentation of disability is not needed
  - Resident of Washington or Oregon

## Contact:

- Website: [www.nwaccessfund.org](http://www.nwaccessfund.org)
- Phone: (206) 328-5116
- Email: [ruth@nwaccessfund.org](mailto:ruth@nwaccessfund.org)

## Questions & Answers:

Q: In transition from child to adult SSI, does the SSI automatically transfer over or do they need to reapply?

A: No, they do not need to reapply, but they do go through a process called the Age 18 Redetermination process.

Q: Is the application the same regardless of what age the caregiver submits under 18?

A: Yes, the application is the same, regardless of the age.

Q: Is this information in other languages?

A: Social Security does translate a lot of their information and documents into several different languages. Regarding the presentation, no, there are no other translated languages.

Q: Do NW Access Fund have attorneys to help with SSI process?

A: No, but NW Access Fund gives families referrals.

Q: Spend down: any restrictions?

A: There are some restrictions on Spend down. Basically, it has to be for the kid and can't be spent on other people.

Q: What happens if there is no guardianship/power of attorney/etc, at age 18?

A: If there's no guardianship or power of attorney, you can help the child apply and it will ask on the application.

Q: Do families still need to keep a log of how the SSI funds are spent?

A: You do need to keep records.

## Kids Mental Health Washington: Youth Regional Behavioral Health Navigators

Gina Cabiddu, Kids Mental Health; Meghan Hopkins, DDA; Edward Michael, HCA

- On March 15, 2021, Governor Jay Inslee signed an emergency proclamation recognizing the current mental and behavioral health emergency among Washington's children and youth.
- Behavioral health crises come in many forms, and most do not fit neatly into a categorical service box.
- No single entity or system owns full responsibility for crises, and a single entity or system is not, on its own, sufficiently leveraged to address the multi-factored complexities necessary for a healthy system.
- Given the multifactorial determinants of psychiatric boarding in the ED, potential solutions will require a variety of hospital strategies, external community strategies, ideally in collaboration with one another.

## Youth Regional Behavioral Health Navigator Program:

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The Health Care Authority (HCA) is partnering with Kid’s Mental Health Pierce County and Developmental Disabilities Administration (DDA) to stand up teams in three regions per year for the next three years.

Technical assistance and support, collaborative learning teams and pathways for real time input on regional strengths and needs are being developed as teams begin standing up across the state.

Regional teams are building community in support of children, youth, and families through the development of Multi-Disciplinary Teams (MDT). Key partners including community members, providers, and cross-systems team members are gathering to connect our youth and families to the care and resources they need.

#### **Cross-System Collaboration:**

- Autism and Disability Partners
- Child Welfare
- School Districts
- Youth Services
- Health Equity Partners
- Health Care Systems
- Primary Care
- Community Mental Health
- Crisis Services
- Managed Care Organizations
- Law Enforcement Juvenile Justice
- EMS

#### **Community Multi-Disciplinary Teams (MDT)**

- Natural Supports
  - Family
  - Peer/Parent Support
  - Mentors
- Payor
  - Insurance Provider
  - BH-ASO
  - HealthCare Authority
- System Partners
  - Juvenile Justice
  - Child Welfare
  - School
- Providers
  - Behavioral Health Providers
  - Specialist
  - Substance Use Providers

#### **Developmental Disabilities Administration:**

DDA has several positions supporting the Youth Behavioral Health Navigator Program

- Respite and Short-Term Services Unit Manager (Shelley Bogart).
- Youth Behavioral Health Navigator Program Manager (Meghan Hopkins).

- Youth Regional Behavioral Health Navigators (in development).
  - One Navigator for each of the three DDA regions.

DDA's role includes

- Partnering to support youth with developmental disabilities and their families in navigating service systems.
- [DDA Eligibility and Services Guide](#)
  - Improving cross-systems communication for more efficient collaboration.
- Addressing barriers to services including developing and disseminating resources to increase provider confidence in serving youth with developmental disabilities.
  - [The Guidebook: Meeting the mental health needs of people with intellectual disabilities \(wa.gov\)](#)
  - [Mental Health and Developmental Disabilities National Training Center Resources](#)

## Youth Behavioral Health Navigator Rollout

 **Year 1 SFY 2022**

- [Pierce](#)
- [Salish](#)
- [Greater Columbia](#)
- [Southwest](#)

 **Year 2 SYF 2023**

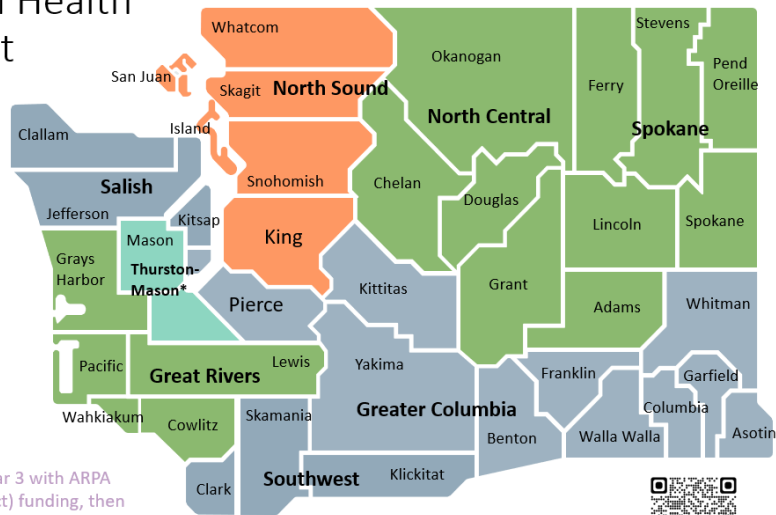
- North Central
- Spokane
- Great Rivers
- Thurston-Mason\*

 **Year 3 SFY 2024**

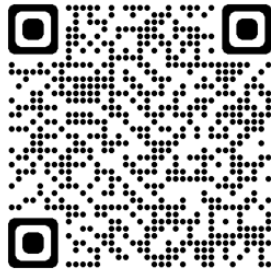
- North Sound
- King

 **Thurston-Mason**

- Start year 2 instead of year 3 with ARPA (American Rescue Plan Act) funding, then will move to state funding



# Contacts



<https://kidsmentalhealthwa.org/>

The Health Care Authority (HCA)	Technical Assistance and Support	Developmental Disabilities Administration (DSHS DDA)
<p><b>Diana Cockrell, MA, LMHCA, SUDP</b> Section Manager, Prenatal to 25 Lifespan Behavioral Health &amp; Substance Use <a href="mailto:Diana.Cockrell@hca.wa.gov">Diana.Cockrell@hca.wa.gov</a></p> <p><b>Ruth Leonard, MA, SUDP</b> Section Manager, Strategic Design &amp; Program Oversight <a href="mailto:Ruth.Leonard@hca.wa.gov">Ruth.Leonard@hca.wa.gov</a></p> <p><b>Edward Michael, MS</b> Statewide Youth Behavioral Health Access Administrator <a href="mailto:Edward.Michael@hca.wa.gov">Edward.Michael@hca.wa.gov</a></p>	<p><b>Ashley Mangum, MSW, LICSW</b> Director, KMHPC <a href="mailto:Ashley.Mangum@multicare.org">Ashley.Mangum@multicare.org</a></p> <p><b>Vanessa Adams, MSW, LICSW</b> Program Coordinator—KMHPC <a href="mailto:Vanessa.Adams@multicare.org">Vanessa.Adams@multicare.org</a></p> <p><b>Gina Cabiddu, MSW</b> Program Coordinator <a href="mailto:Gina.Cabiddu@multicare.org">Gina.Cabiddu@multicare.org</a></p> <p><a href="http://www.kidsmentalhealthpiercecounty.org">www.kidsmentalhealthpiercecounty.org</a></p>	<p><b>Shelley Bogart</b> Respite and Short-Term Services Unit Manager <a href="mailto:Shelley.Bogart@dshs.wa.gov">Shelley.Bogart@dshs.wa.gov</a></p> <p><b>Meghan Hopkins, MA, LMHC</b> DDA Youth Behavioral Health Navigator Program Manager <a href="mailto:Meghan.Hopkins@dshs.wa.gov">Meghan.Hopkins@dshs.wa.gov</a></p>

<https://kidsmentalhealthwa.org/> (All of Washington)

<https://kidsmentalhealthpiercecounty.org/> (Pierce County)

Questions and Answers:

Q: How will the navigator program interface with the DDA CIIBS Program?

A: Since it is a waiver, that is available to youth who have, exhausted some of the lower levels of support that DDA offers. <https://fortress.wa.gov/dshs/adsaapps/about/factsheets/DDAFactsheets.aspx>

Q: Is there a similar program like the navigator program happening for adults?

A: Youth are eligible for EPSDT through age 21

Q: Who is organizing the regional pages and this effort?

A: Each of these regions has a team of at least 3. They are constantly updating their own websites. They are hosting their own multidisciplinary teams and they're convening those steering and action committee meetings.

## Autism and Suicide

Zack Siddeek, MSW

### Who is Zack? (He/Him)

- Grew up in Western Colorado.
- Mix of Italian, Iraqi, and German.
- Diagnosed with PDD-NOS at 11.
- B.A. from Evergreen in everything 2013.
- MSW from UW in 2018.
- Disability Systems Navigation Coordinator,
- Arc of King County
- Organizer of the Square Pegs

### Autism and Queer Intersection:

WASHINGTON STATE DEPARTMENT OF HEALTH  
COMMUNICATION NETWORK MEETING MINUTES – 01/11/2024

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- From Zack's survey:
  - Heterosexual- 80 (58.39%)
  - Bi/Pansexual- 31 (22.63%)
  - Homosexual- 12 (8.76%)
  - Asexual- 5 (5.11%)
  - Heteroflexible, ginosexual, demi-bi, queer, variable/uncategorized, Grayasexual
    - Preferred not to answer- 1 in each of the above (.73%)

## **Autism and LGBTQIA +**

One study found that 20% of people being treated for gender dysphoria displayed Autism-like signs. (Van Der Miesen, Hurley & De Veries, 2016)

Sexual and Gender minority groups experience poorer mental health outcomes. Many therapists who work with the queer community may not be Autism competent.

Studies show that Queer Autistic people have worse mental health outcomes than those are either Queer people or Autistic people. (George & Stokes, 2018)

### **Autistic Women:**

In a survey I conducted of 144 Autistic adults in Washington State, I found that Autistic women were diagnosed 12 years later on average compared to Autistic men.

Most trainings will tell you that there are 4 Autistic men to every 1 Autistic woman. This is not correct. The ratio becomes much less when looking at Autistic people with high support needs.

Autistic women tend to be diagnosed with ADHD, Depression, Bi-Polar Disorder type ii, or Borderline Personality disorder - and may receive inappropriate medications.

### **Masking:**

Masking is camouflaging or hiding external signs of being Autistic for the comfort of the non-Autistic people around.

Research literature shows that Autistic girls are far more likely to mask differences than Autistic boys. The process appears to start in pre-school. (Sutherland et al. 2017.) The masks typically start to crack in middle school.

Masking is linked to anxiety and depression in Autistic folks.

One study showed the masking was the biggest predictor for suicidal ideation in Autistic adults. (Cassidy et al. 2018)

Masking is also directly linked to Autistic burnout.

### **Autistic Burnout:**

Prolonged periods of intense masking and stress seem to be the biggest factors.

During burnout, Autistic people can lose the skills and abilities they could count on, like cleaning the house, driving a car, working a 40-hour job, or even speaking.

Autistic burnout is a state of prolonged mental, physical, and emotional exhaustion.

### **All of this has an impact:**

The suicide rate for the Autistic Community is 9x the general population's rate.

31% of Autistic people report sexual assault/rape at least once in their lifetime.

Autistic people may be likely to engage in substance use as a coping mechanism.

Autistic people are more likely than the general population to have experienced homelessness.

### What is the impact in Washington State?

- In a survey of 147 Autistic people in Washington state I did in 2019, 47 reported suicidal ideation within the past 30 days.

### What does the research show?

- Cassidy et al. (2018) found 72% of the 164 Autistic people in the study scored above the psychiatric cut off risk for suicide, compared to 33% of the 169 non Autistic participants.
- A meta analysis by O'Halloran, Coey & Wilson (2022) on suicidality in Autistic youth found in the 47 papers analyzed, 25.2% of the Autistic youth had suicidal ideation, 8.3% had attempted suicide, and .2% had died from suicide.

### What are the factors that leads to suicidal ideation?

- O'Halloran, Coey & Wilson (2022) found ACES were a predictive factor & that Trans Autistic youth were at greater risk.
- Co occurring ADHD without intellectual disability appears to be the most at risk group for suicidal behaviors. Autistic people with intellectual disability were also higher risk. Hirvikoski et al. (2019)
- Cassidy et al. (2018) found that the highest unique risk markers for suicidality were camouflaging (aka masking,) and unmet support needs. Non unique risk markers include Non-suicidal self-injury, employment, and mental health problems.

### Recommendations:

- Be proactive and talk to the Autistic youth and adults you are working with about suicidal ideation in addition to screening tools. The existing screening tools like the PHQ9 do not appear to accurately reflect risk. (Carter et al. 2017; Wang et al. 2016)
- Cassidy et al. (2021) adapted a screening tool called the suicidal behaviors questionnaire (SBQ) to use with Autistic people. The SBQ-ASC showed promise, but the authors cautioned more research needs to be done to determine its usefulness in clinical populations.
- Make the tools you use with Autistic people accessible. (I.e. Plain Language, checklists, visual format, concrete language, ect.)
- Autistic people without DDA services (and even many with) have few if any Autism affirming mental health services. This needs to change.
- Consider how we can provide supportive services to Autistic non-speakers and those with intellectual disabilities.
- Consider using the Minority Stress Model as a way to conceptualize how the experiences of Autistic people and not Autism itself is the reason for the high suicide rates. (Botha & Frost, 2020) Consider the Social vs Medical model of disabilities.
- Stigma is the root reason why the suicide rate is so high for Autistic people. What can you do to end the stigma we encounter everyday?

### Contact:

- Zack Siddeek: [Zsiddeek@ArcofKingCounty.org](mailto:Zsiddeek@ArcofKingCounty.org)
- <https://www.meetup.com/squarepegs/>

### Question & Answers:

Q: What is the age group for Square Peg?

A: 18+

## **MCHBG Needs Assessment: Facilitated Discussion**

Mary Myhre, WA Department of Health

### **What the Needs Assessment Is:**

Every five years, the Washington State Department of Health completes a comprehensive assessment of the health of children, parents and caregivers, and families in the state. The assessment is a requirement of the Title V Maternal and Child Health Block Grant. It includes analyzing existing reports and data, as well as conducting interviews with health care, public health, and community leaders to gain their perspectives on the health needs of families.

### **What We Need From You:**

As you respond to the primary needs assessment questions today, we ask that you think about the questions through the lens of health equity and justice, social determinants of health, prevention and life course, and the role of partnerships. We strongly encourage you to use your full breadth of experience and perspective, and to not think about the questions based solely on your role as an employee of an organization or as a member of a workgroup.

Please Contact Mary Myhre at [Mary.Myhre@doh.wa.gov](mailto:Mary.Myhre@doh.wa.gov) for any questions.

Discovery Survey link to distribute: [Discovery Survey - Maternal and Child Health \(surveymonkey.com\)](#). Available in several other languages.

## **CSHCN Coordinator Updates by County**

Gathered from counties and shared on a quarterly basis.

### **Grays Harbor County Public Health**

*Stefani Joesten, CYSHCN Coordinator*

### **Grant County Health District**

*Maria Vargas, CYSHCN Coordinator (temporary)*

Maria is the temporary CYSHCN Coordinator contact for Grant county, while they actively hiring for the position.

### **Island County Public Health**

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

### **Jefferson County Public Health**

*Cynde Marx, CYSHCN Coordinator*



**Pacific County Public Health and Human Services**  
*Brianne Cline, CYSHCN Coordinator*

**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*

Leading Yakima County Care Coordinator's meeting with recent presentations from DDA and Children's Village ABA program.

Chairing local Central Washington Interagency Transition (to adulthood) Network meetings.

Participating in WA Blueprint for Change meetings with State CYSHCN.

On-going care coordination activities with families of CYSHCN.

## Neurodevelopmental Center (NDC) Updates

**Peace Health Children's Therapy - Whatcom County**  
*Kris Gaggero, Clinic Manager*

**Children's Therapy Skagit Valley Hospital**  
*Erin Kavi, Lead Therapist*

[www.skagitvalleyhospital.org](http://www.skagitvalleyhospital.org)

**Children's Therapy Valley Medical Center**  
*Kari Tanta, Rehab Manager*

[www.valleymed.org](http://www.valleymed.org)

## **Kindering**

**Kathy Fortner Director of Operations**

[www.kindering.org](http://www.kindering.org)

## **HOLLY RIDGE**

**Alicia Skelly, Infant Toddler Program Director**

## **Children's Therapy Center**

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

## **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 change their name to Wellpoint.*

### **Community Health Plan of Washington (CHPW)**

[www.chpw.org](http://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**

[www.coordinatedcarehealth.com](http://www.coordinatedcarehealth.com)

### **Molina Healthcare of Washington**

**Kelly Anderson, MBA, BS, Rn, CCM**

[www.molinahealthcare.com](http://www.molinahealthcare.com)

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No updates at this time.

**UnitedHealthcare**  
**Cassie Mitson, RN, CPN**

[www.uhc.com](http://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

Washington State Parent to Parent provided support and information to 4,796 parents and caregivers October-December!

The Network had the following professional development:

October- Legislative Advocacy and 2024 DD issues (with Diana Stadden, The Arc of WA)

November- Washington State Paid Family Medical Leave (with Evans School of Public Policy & Governance, University of Washington)

Parent quote:

'Parent to Parent has been a lifeline for my family and we have made lifelong friends through the program!'

### Washington State Medical Home Partnerships Project for CYSHCN

#### Kate Orville

[www.medicalhome.org](http://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 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, PhD a 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 and Sarah Harsh, 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 CSHCN 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.*

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

## **Washington State Fathers Network (WSFN)**

**Matthew Rickmon, Director**

[www.fathersnetwork.org](http://www.fathersnetwork.org)

## **Family to Family Health Information Center (F2FHIC)**

**Jill McCormick**

[www.familyvoicesofwashington.com](http://www.familyvoicesofwashington.com)

*No updates at this time.*

## **Open Doors for Multicultural Families**

[www.multiculturalfamilies.org](http://www.multiculturalfamilies.org)

*No updates at this time.*

## **Washington Autism Alliance & Advocacy (WAAA)**

[www.washingtonautismadvocacy.org](http://www.washingtonautismadvocacy.org)

*No updates at this time.*

## Office of Superintendent of Public Instruction (OSPI)

[www.k12.wa.us/HealthServices/default.aspx](http://www.k12.wa.us/HealthServices/default.aspx)

## Seattle Children's Hospital

[www.seattlechildrens.org](http://www.seattlechildrens.org)

*No updates at this time.*

## Lifespan Respite Washington (LRW)

**Linda Porter**

[www.lifespanrespitewa.org](http://www.lifespanrespitewa.org)

*No updates at this time.*

## WithinReach

[www.withinreachwa.org](http://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](http://www.dcyf.wa.gov/esit)

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

*No updates at this time.*

## **DSHS / DDA, Medically Intensive Children's Program**

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

*Autumn Wade and Amanda McCleskey*

## **DSHS / ALTA, Kinship Care and Lifespan Respite**

[www.dshs.wa.gov/kinshipcare](http://www.dshs.wa.gov/kinshipcare)

*No updates at this time.*

## **DOH Screening and Genetics Unit**

[www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/GeneticServices.aspx](http://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 11, 2024

Virtual Meeting