Washington State Department of HEALTH

CYSHCN ORIENTATION

Children and Youth with Special Health Care Needs

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Who are Children and Youth with Special Health Care Needs?

CYSHCN are children that:

- **Have or are at increased risk** for chronic physical, developmental, behavioral, or emotional conditions
- Require health and related services of **a type or amount beyond that required** by children generally

Definition from National Standards for CYSHCN

Our Partners

Workforce Development

- UW Medical Home Partnerships Project
- UW IHDD Nutrition Network

Family Engagement

- PAVE: Partnerships for Action, Voice for Empowerment
- Parent to Parent (P2P)
- Washington State Father's Network
- Washington State Leadership Initiative

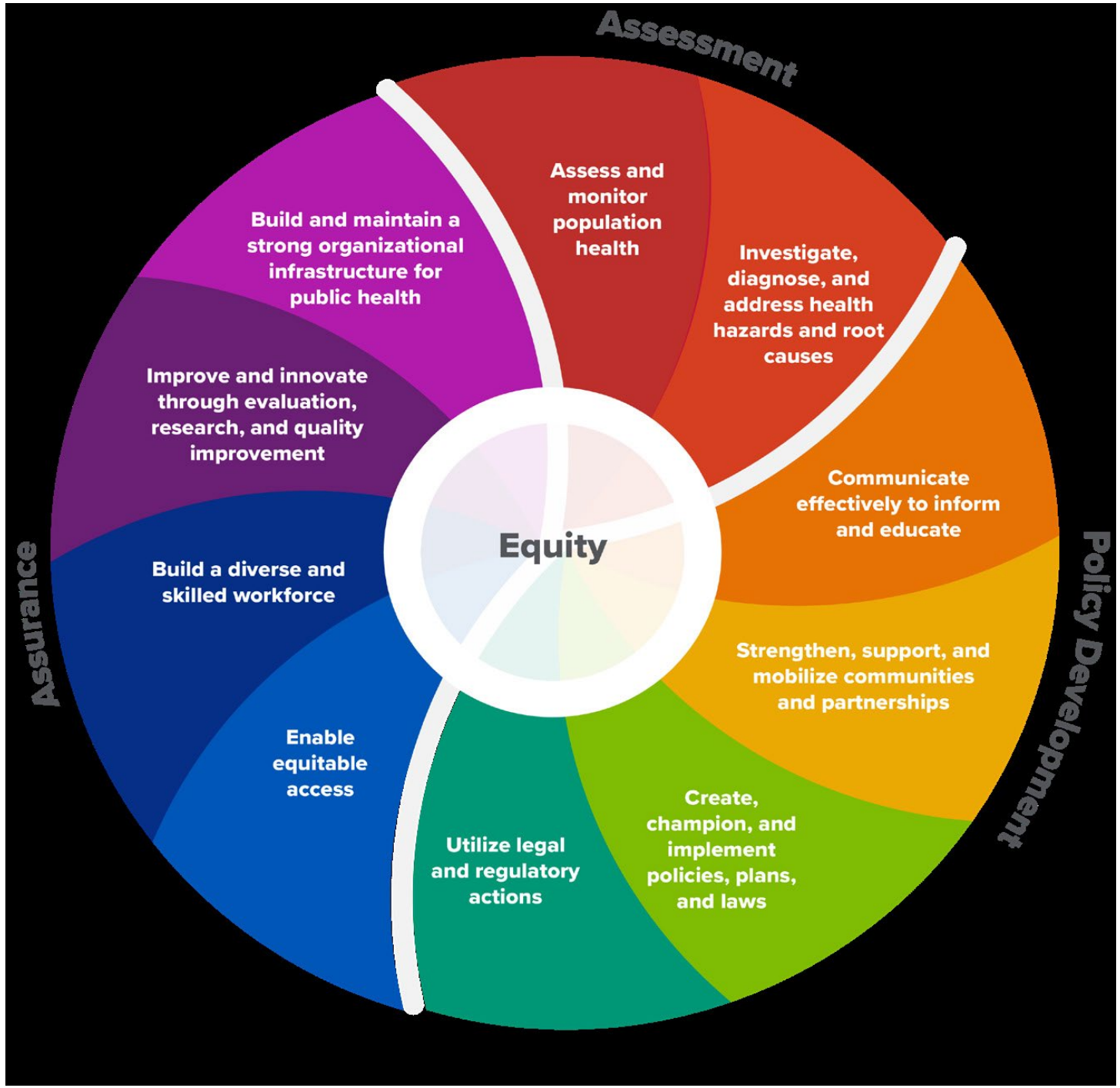
Providers

- LHJ CYSHCN Coordinators
- Neurodevelop-mental Centers of Excellence (NDCs)
- Maxillofacial Review Boards (MFRBs)
- Seattle Children's
- Within Reach

What makes a child CYSHCN Eligible?

Children are eligible to receive CYSHCN services if:

- They have:
  - disabilities and/or handicapping conditions;
  - health-related educational or behavioral challenges
- Are 17 years of age or younger*
- Are residents of Washington State*
- *Can support existing clients with transition through age 20

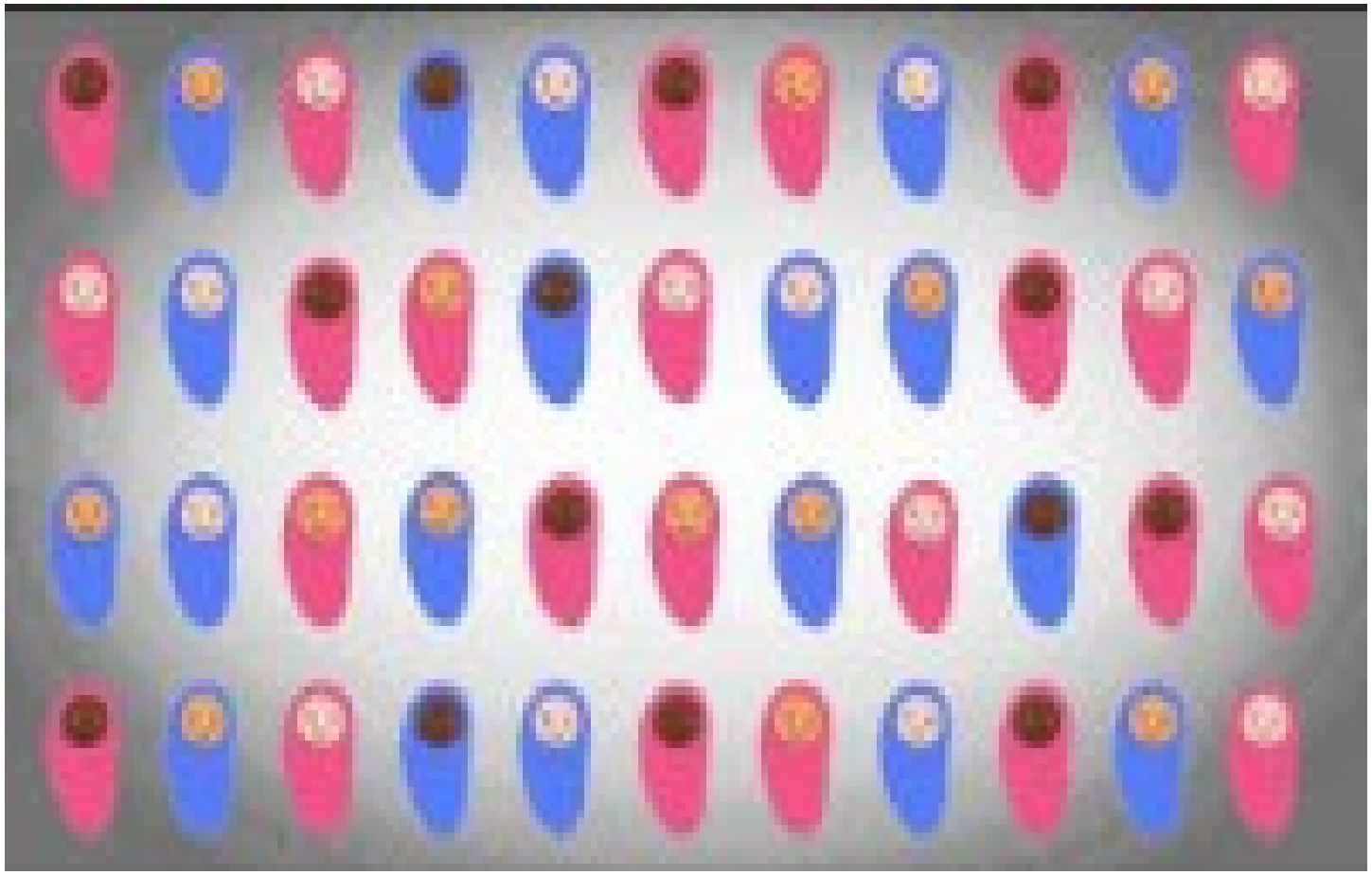

Assessment
Assess and monitor population health
Investigate, diagnose, and address health hazards and root causes
Policy Development
Communicate effectively to inform and educate
Strengthen, support, and mobilize communities and partnerships
Create, champion, and implement policies, plans, and laws
Utilize legal and regulatory actions
Assurance
Enable equitable access
Build a diverse and skilled workforce
Improve and innovate through evaluation, research, and quality improvement
Build and maintain a strong organizational infrastructure for public health
Equity

Background & Context

Title V: Maternal and Child Health (MCH) Services Block Grant

- Federal program
- Focuses solely on improving the health and wellbeing of mothers, children and infants
- Development and coordination of systems of care that are family-centered, community-based, and culturally appropriate
- Complete needs assessments every 5 years to identify focus areas within the state.
- Report on progress in the work towards those goals each year
- 30% of State MCH Block Grant funds - preventative and primary care services for children
- 30% of State MCH Block Grant funds - services for CYSHCN

Origins of Title V:



How Title V Makes Difference

- Improving Birth Outcomes and Maternal Health
- Breastfeeding Promotion
- Newborn Screening
- Ensuring Child Immunizations
- Early Childhood Programs and universal development screening
- Teen Pregnancy Prevention Services

- Children and Youth with Special Healthcare Needs:

Promotes a system of care that is family-centered, integrated, collaborative, coordinated, and equitably accessible to all CYSHCN and their families.

How do we get there?

- The *National Care Coordination Standards for Children and Youth with Special Health Care Needs* are designed to help state health officials to:
  - Address state-level challenges, including identifying the needs of CYSHCN;
  - Support and engage families of CYSHCN in care coordination;
  - Train the care coordination workforce; and
  - Improve other aspects of quality care coordination systems.
- Developed with input from a national work group which included families of CYSHCN, state Medicaid agencies, public health, researchers, children's hospitals, health plans, health plan certification entities, provider groups, and other stakeholders.
- They define the core components of a comprehensive, coordinatized, and family-centered system of care for CYSHCN

Blueprint for Change:
A National Framework for a System of Services for CYSHCN

Federal vision to advance the system of services for CYSHCN over the next 15 years.

Blueprint goal in plain language: Every child gets the services they need, so that they can play, go to school, and grow up to become a healthy adult. (And so grown-ups and siblings can thrive too.)

Critical Areas for a Well-Functioning System

New Federal Blueprint for Change

Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and their Families:

- **Health Equity**
- **Family/Child Well-being and Quality of Life**
- **Access to Services and Supports**
- **Financing of Services**

This special supplement in *Pediatrics* is freely available

Critical Areas for a Well-Functioning System

National Center for a System of Services for Children and Youth with Special Health Care Needs (aap.org)

CYSHCN Strategic Planning Goals

System of Care

Family-centered
Integrated
Collaborative
Coordinated
Equitable

Funding

Improve Access
Flexibility
Families & Providers
Best Practices

Equitable Access

High Quality Care
Underserved Populations
Systemic Racism

Concrete Supports for Well Being

Social/Emotional Support
Belonging & Inclusion
Mental Health & Behavior

Family Navigation & Care Coordination

For Complex Health, Socioeconomic, & Psychosocial Needs of CYSHCN & Families

CYSHCN Focus of Work: Required Activities

- **Complete intake and renewal process into Child Health Intake Form (CHIF)**
- **Share updated information on your local CYSHCN program with Within Reach / Help Me Grow (HMG)**
- **Administer Diagnostic and Treatment Funds** for infants and children **as needed**
- **Dedicate at least 30% of your total MCHBG budget to CYSHCN**.
- ***Select at least one Local Strategy to address CYSHCN***.

Child Health Intake Form (CHIF)

CHIF Administrator

Amanda Simon

Email:
amanda.simon@doh.wa.gov

Phone Number:
(564) 669-9285

WHO?

Reporters Include: Local Health Jurisdictions, Maxillofacial Review Boards, and Neurodevelopmental Centers of Excellence.

CHIF Vocabulary

CHIF: Child Health Intake Form

MFT: Managed File Transfer

CHIF Spreadsheet: The spreadsheet supplied to you from DOH.

Child Health Intake Form - AKA CHIF

CHIF flags CYSHCN children in ProviderOne and informs MCOs about the need for additional care coordination and other supports and services.

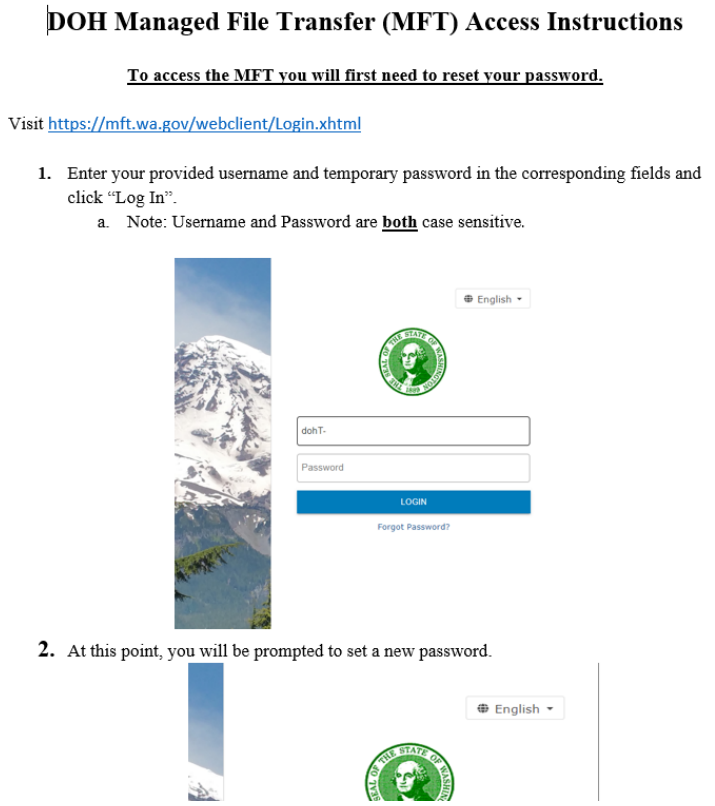
~18,000 children CHIF'ed in WA state per year

Programs can use CHIF data for:

- Program planning and evaluation
- Responding to requests for information
- Providing information to funding sources and authorities
- Meeting federal Title V requirements

The MFT (Managed File Transfer)

- CHIF Reports are sent via Managed File Transfer (MFT).
  - The MFT can be found at the following site: mft.wa.gov
  - New staff: an MFT account will need to be set up under your name and/or organization.
- Please submit a ticket via- Survey Monkey this will start the process of getting your MFT account set up.
  - Once the CHIF administrator has received your ticket expect them to reach out to you to set up a CHIF specific onboarding.



DOH Managed File Transfer (MFT) Access Instructions

To access the MFT you will first need to reset your password.

Visit https://mft.wa.gov/webclient/Login.xhtml

1. Enter your provided username and temporary password in the corresponding fields and click "Log In".
   a. Note: Username and Password are **both** case sensitive.

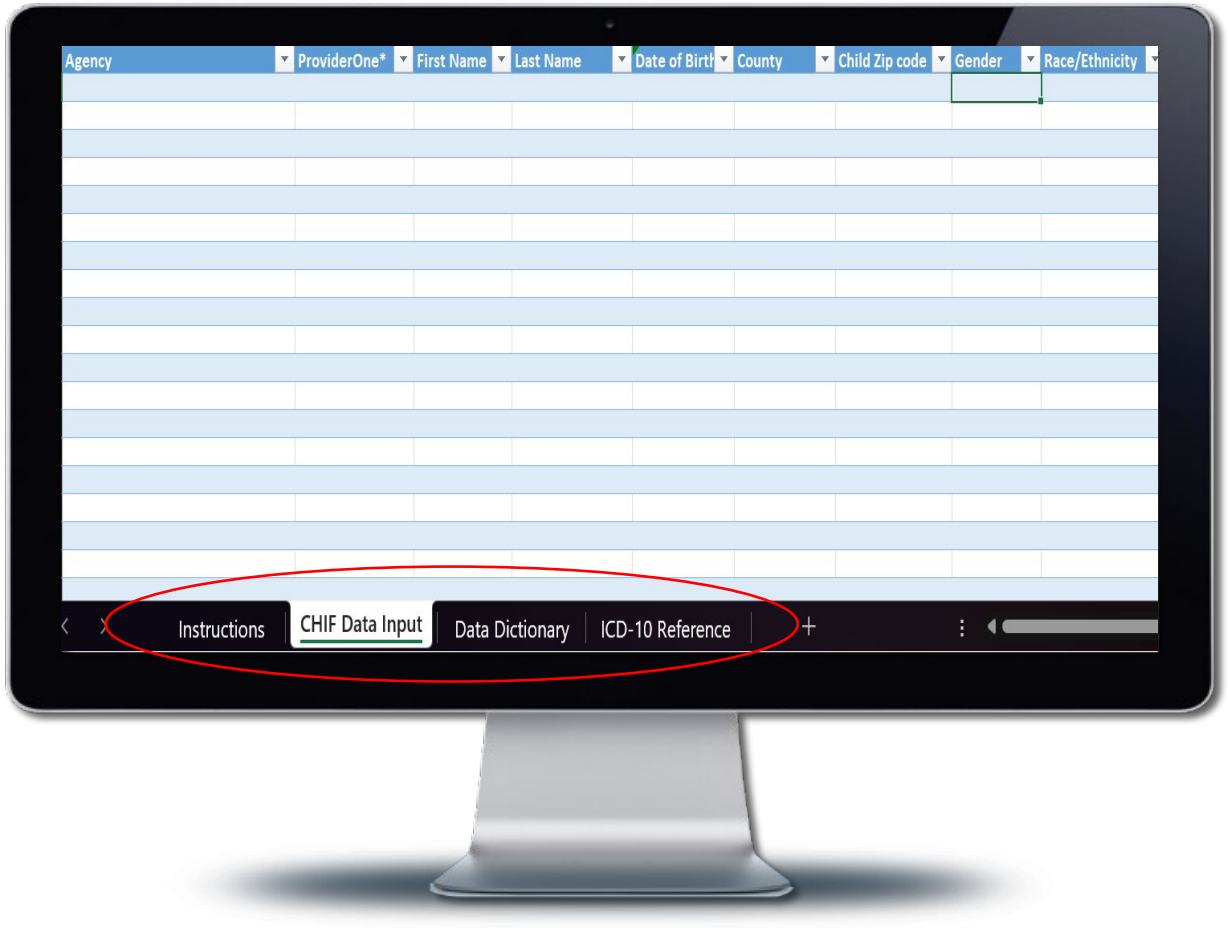
2. At this point, you will be prompted to set a new password.

CHIF Reporting Requirements

- With caregiver consent infants and children receiving assistance and accessing services through the CYSHCN Program need to be CHIF'ed.
- If you have zero clients to report for the quarter, you are still required to report.
  - Instead of submitting a spreadsheet to the MFT, please email the CHIF inbox at DOH-CHIF@doh.wa.gov that you are submitting a report with zero clients.
- CHIF Reports are due:
  i. October 15th
  ii. January 15th
  iii. April 15th
  iv. July 15th
- If you are not providing direct or enabling services to families of CYSHCN, you do not need to submit CHIF data.

The CHIF Spreadsheet

Once you receive the CHIF spreadsheet please take some time to review all the tabs on the excel document.



Final Notes

CHIF Office Hours

- 4th Wednesday of the month
- Office hours are held at 11am.
- They are space to ask questions of me, the CYSHCN Epidemiologist, or hear a guest speak.

New CYSHCN Coordinators

- Please remember to submit your ticket to survey monkey the link can be found here- https://www.surveymonkey.com/r/LGYDQLR

Diagnostic and Treatment Funds (Dx/Tx)

Small pot of funds available to CYSHCN for **medically necessary services/resources** that are not covered by any other funding source

2025-2026: $5,000.00 available for Washington State

Should be the payor of last resort - all other potential payers/resources have been sought without success of coverage for the requested funds

In alignment with Washington Administrative Code 246-710-050.

Diagnostic and Treatment Funds (Dx/Tx)

Who Is Eligible?

CYSHCN who meet **all** of the following:

- The request is from a qualified provider accompanied by an evaluation
- The service/product is considered **medically necessary** and is evidenced based in research
- The request is for a client who has Apple Health Managed Care Plan medical coverage (Medicaid)
- The service/resource request has been denied by Medicaid, MCOs, and other potential payers **AND** an appeal for the denial has been rejected from potential payers.
- Payor of last resort

Diagnostic and Treatment Funds (Dx/Tx)

How to Request Funds?

- Reach out to the Dx/Tx lead for a consult if you think your client may be eligible: **Khimberly.Schoenacker@doh.wa.gov**

- If the client is eligible after reviewing the Dx/Tx document: complete a Health Services Authorization (HSA) form for submission to the CYSHCN program for review

Children with Special Health Care Needs (CSHCN)
HEALTH SERVICES AUTHORIZATION
Asterisk (*) = Required Data for Payment

			AUTHORIZATION NO.
1. PATIENT*:	Martha A Washington	2. PROVIDERONE (P1) ID*	123456789WA
		3. CHIF ID (if P1 not available)	
4. ADDRESS:	2014 Cherry Blossom Lane, Olympia, WA 98501		10. BIRTH YEAR* 2014
5. DIAGNOSIS*:	734		11. COUNTY OF RESIDENCE & CODE* 34-001
6. VENDOR OR PROVIDER*	Olympia Orthotics 2014 Capitol Boulevard Olympia, WA 98501	RETURN AUTHORIZATION BY	12. AUTHORIZATION DATE* 5/1/2014
			13. AUTHORIZATION EXPIRES* 7/1/2014
7. VENDOR/PROVIDER FEDERAL TAX ID NO.* 91-90000000	8. VENDOR/PROVIDER NPI 9090909090	9. VENDOR/PROVIDER TAXONOMY 335E00000X	14. INSURANCE/POLICY NO./NAME* Not covered by Medicaid

You are authorized to perform the following services for which CSHCN will be obligated to pay their fee, according to currently established payment policy or fee schedule. For payment questions and additional services not specified nor ordinarily included as a part of the description, contact local agency indicated at bottom.

CYSHCN Communication

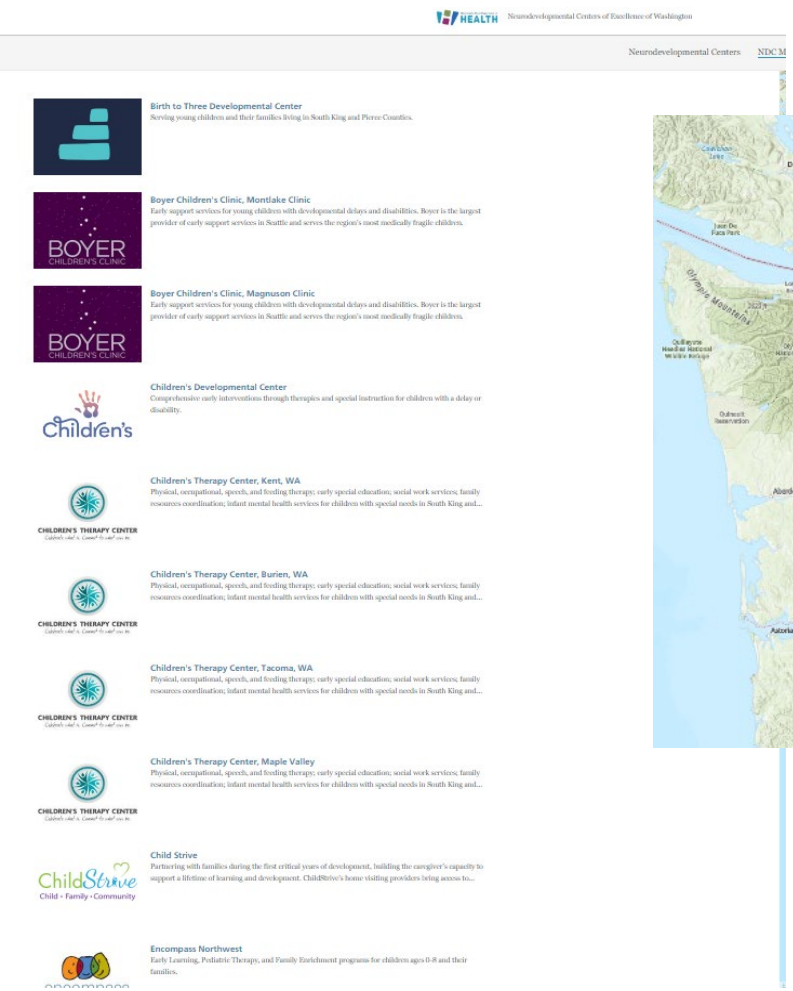
- CYSHCN Brochure
  - How to order
- Quarterly CYSHCN Communication Network Meetings
  - CYSHCN Communication Network Newsletter
- New Coordinator Orientation
- Quarterly CYSHCN LHJ/MCO Call Meetings
- New LHJ Meet & Greets
- CYSHCN website updates
- CYSHCN partner contact updates, please email Linda Ramirez at Linda.Ramirez@DOH.WA.GOV.

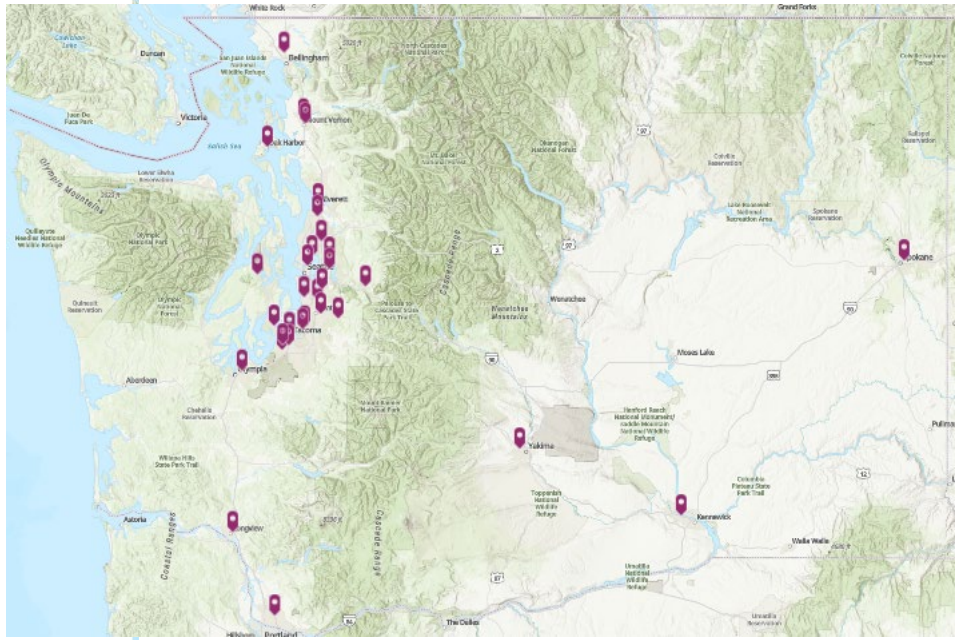
Basecamp


Home
Lineup
Pings
Hey!
34
Activity
My Stuff
Find
CYSHCN Coordinator Collaboration and Resource Tool
This is a space for CYSHCN Coordinators to access resources, collaboration, and support among their peers and DOH
Set up people
Message Board
Gas Voucher?
Question — Hi, I had one of our elementary
Editable diaper brochure and MCO Case Management fact sheet
CYSHCN System Work
Pitch — *This message board will be used to
Spokane Family Support Conference 11 15 24
Hello Community Partners, We are organizing a
Facing Fentanyl Event tomorrow Sept 20
Announcement — Facing Fentanyl Together |
To-dos
Organize work across teams. Assign tasks, set due dates, and discuss.
Make a to-do list
Docs & Files
Inclusive Language Playbook
Brochure-Need-Diapers 6 24.pdf
Fact-Sheet-Managed-Care-Organization-...
Report on Infant Mental Health in our state
CYSHCN Program Materials
CYSHCN Orientation Materials
Collaboration Chat
I would also see if the family is willing to contact t...
Janet Wyatt 12:29pm
There is a place in Federal Way, I am not recalling
Jan Schmalenberger 8:04am
Thank you Jordan, I will be bookmarking this web...
Bonnie Peterson 12:44pm
Just saw this resource in Lewis County https://ww...
Jordan Labayen 4:26pm
In case anyone is curious how MCHBG spending a...
Schedule
MON, FEB 3
CYSHCN New Coordinator Orientation
9:00am - 12:00pm
MON, MAR 10
CYSHCN Coordinator/MCO Call
10:00am - 12:00pm
THU, APR 10
CYSHCN Communication Network Meeting
9:00am - 1:00pm
Automatic Check-ins
Send questions to your team on a schedule to get fresh insights.
Ask a question

CYSHCN Early Childhood

- Partner Story Mapping





Children's Village MultiCare Yakima Memorial

Helping children with special health and developmental needs and their families to meet each child's need for individualized care.

Children's Village provides over 30 services to children with special healthcare needs and their families. These include medical specialty clinics, developmental screening, dental services, occupational and speech therapy, mental health counseling, education services, care coordination, and family support, physical therapy.

Family Story:

Most days, Jonah Vogel racing across playgrounds and jumping in puddles with a happy-go-lucky grin taking up half his face. At just 4 years old, his infectious laughter has already won the hearts of countless people, and his mother Jenna couldn't be prouder of how far he's come. Jonah was born premature (at MultiCare Yakima Memorial Hospital) and weighed only 2 pounds, 13 ounces. Jonah had serious issues with feeding, and it took him 2 months in the NICU to put on the few pounds he needed before he could be released. "I felt so supported," says Jenna. They helped set us up for success." At 5 months he was referred to Memorial's Children's Village to start physical therapy. "The Children's Village staff were so knowledgeable and compassionate," says Jenna. When Jonah underwent his first surgery, his family were referred to the Parent-to-Parent support group. "A lot of the families whose children are patients there are part of this group and it became such a blessing to our family." - Children's Village MultiCare Yakima

Website

National Standards of Care for CYSHCN

The *National Standards for Systems of Care for Children and Youth with Special Health Care Needs (CYSHCN)* define the core domains for System Standards as the Following:

- Identification, Screening, Assessment, and Referrals
- Eligibility and Enrollment in Health Coverage
- Access to Care
- Comprehensive care within a Medical Home
- Community Based Services and Supports
- Transition to Adulthood
- Health Information Technology
- Quality Assurance Improvement

*New updated standards in care coordination: https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/

Identification, Screening, Assessment, and Referral

Standards:

- Children are screened early and continuously for special health care needs
- A definition of CYSHCN is in place
- A mechanism for identification of CYSHCN is place for insurance
- CYSHCN receive recommended screenings according to the Bright Futures guidelines
- Screening results are documented and coordinated with the medical home
- Newborn screening results are communicated to families & providers
- Medical home follows up on screening results

What does this look like in WA?

- Children are screened by birthing hospitals/centers, primary care providers, childcare/head start, Within Reach, early intervention providers, and schools.
- Referrals for children go to Early Support for Infants and Toddlers (under 3), NDCs, School Districts and specialty providers, including Autism Centers of Excellence (COEs).
- A new Universal Developmental Screening system – Strong Start
- Children entered in CHIF by CYSHCN Coordinators or NDCs are flagged as CYSHCN for insurance
- Bright Futures guidelines recommend developmental screening at 9,18, and 30 months, with autism screening at 18 and 24 months
- The CYSHCN program contracts with the Medical Home Partnership Project to support primary care practices to develop Centers of Excellence

Who to know – Early Identification, Screening, Assessment & Referral

- birthing hospitals/centers
- primary care providers
- childcare/head starts, Kaleidoscope Play & Learn (KPL)
- Within Reach – Help Me Grow (HMG)
- Early Support for Infants and Toddlers (ESIT) providers
- School district special education
- Neurodevelopmental Centers of Excellence (NDCs)
- specialty providers (OT, PT, SLP, RDN, ABA, beh health, medical specialists)
- Autism Centers of Excellence (COEs), SMART Teams, and diagnostic centers
- Your local Interagency Coordinating Council (ICC)
- Family Support Organizations (e.g., Arc, P2P, PAVE, Father's Network, GBYS)
- Developmental Disabilities Administration (DDA)

Eligibility and Enrollment in Health Coverage

- Children can access medical coverage through Apple Health for Kids
  - Medicaid (no premiums, can be used as secondary coverage)
  - CHIP – small premium (cannot have other coverage)

  https://www.hca.wa.gov/assets/free-or-low-cost/19-003.pdf
- If they do not meet income limits, they may be able to gain coverage through DDA waiver services (goes on child's income instead of family's)
- Medicaid managed care plans offered vary by county
- Managed Care Organizations (MCOs) have care coordinators that can provide extra support for CYSHCN
- Who to know – local insurance navigators and MCO care coordinators.

Community Based Services & Transition

- Get to know your local and regional providers
- DDA is critical for those with developmental disabilities
  - Eligibility is complex
  - Paid services are not guaranteed
  - Important for families to apply AND request services
  - Informing families is a great resource
  - Options for personal care services and respite
  - Transitions services, job coaching, and residential supports
- Get to know the support organizations in your community (e.g., Arc, P2P, PAVE, Father's Network, Guide by Your Side - GBYS, and those service Black, Indigenous, and People of Color - BIPOC communities)
- Can support youth you are working with up to age 20

Access to Care & Medical Home

- Get to know you local and regional providers
- Find ways to track waitlists
- Know who takes Medicaid vs. private insurance
- Work with local primary care practices to support Medical Home

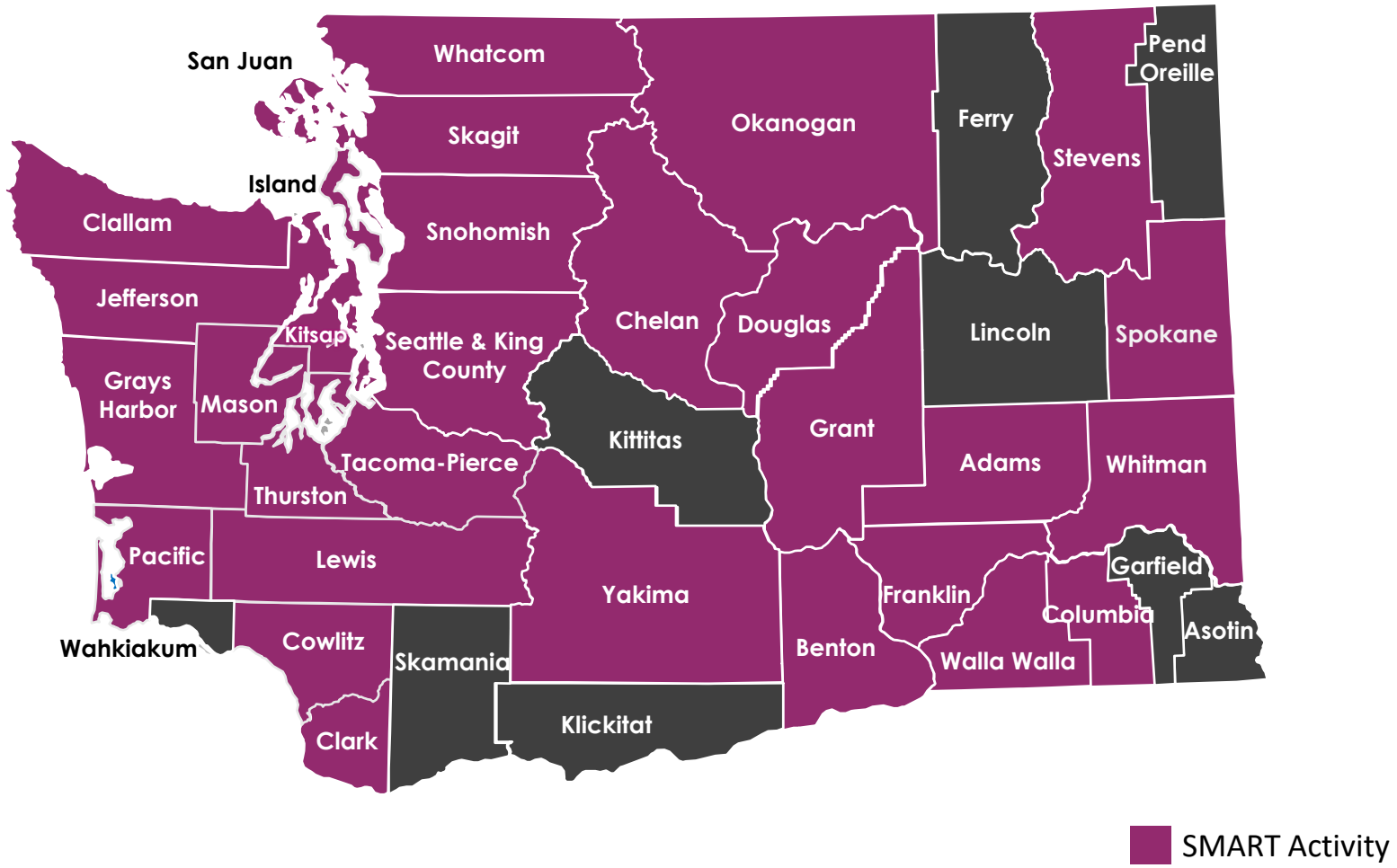
Medical Home

CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.

- All CYSHCN have a medical home capable of providing or coordinating services to meet the child's medical, dental, and social-emotional needs.
- The medical home provides team-based care that is led by a primary care clinician and/or pediatric subspecialist and in which the family is a core member.

School Medical Autism Review Team (SMART) activity by Local Health Jurisdictions

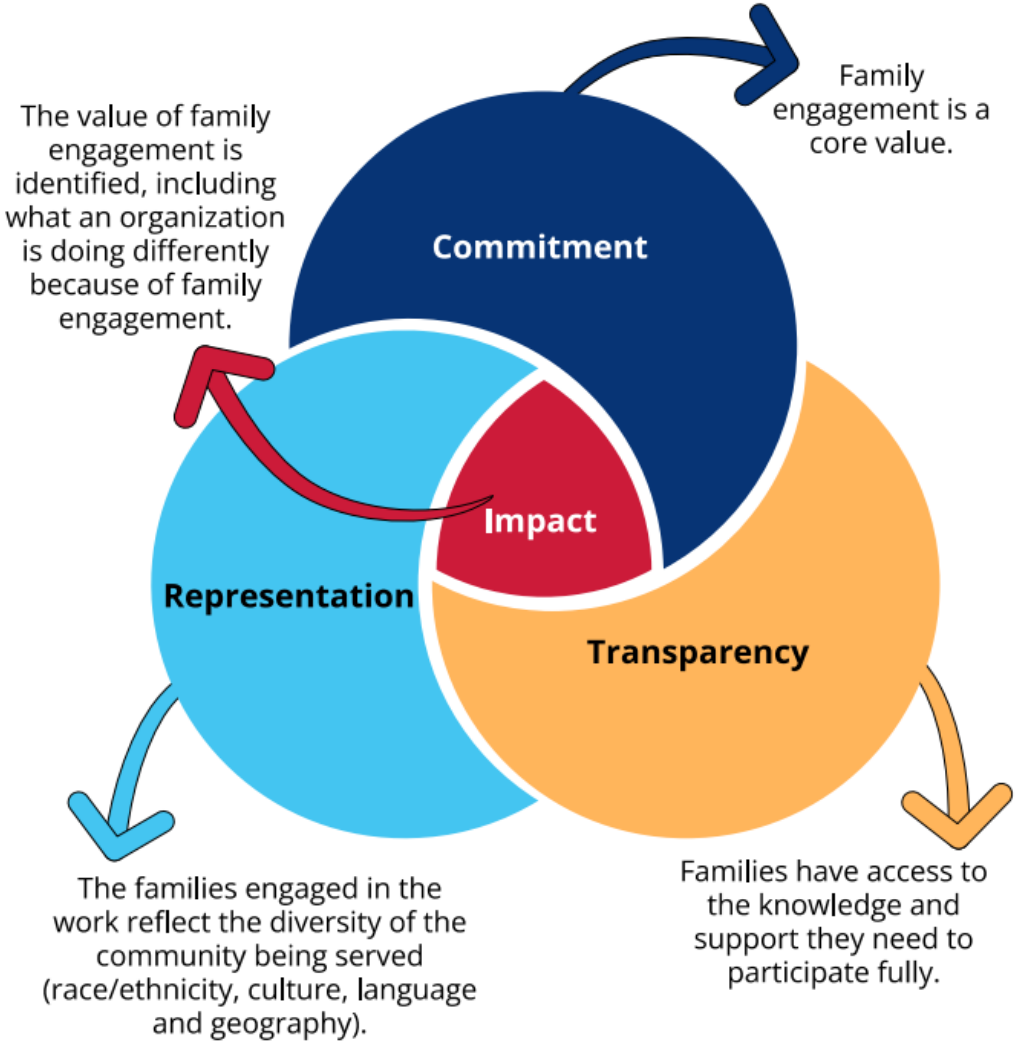
School Medical Autism Review Team (SMART) Activity



Family Engagement in Systems Assessment Tool (FESAT)

4 Domains

- Commitment
- Transparency
- Representation
- Impact



How to Use the FESAT

https://familyvoices.org/fesat/

Families of CYSHCN have Unique Needs

Peer Supports

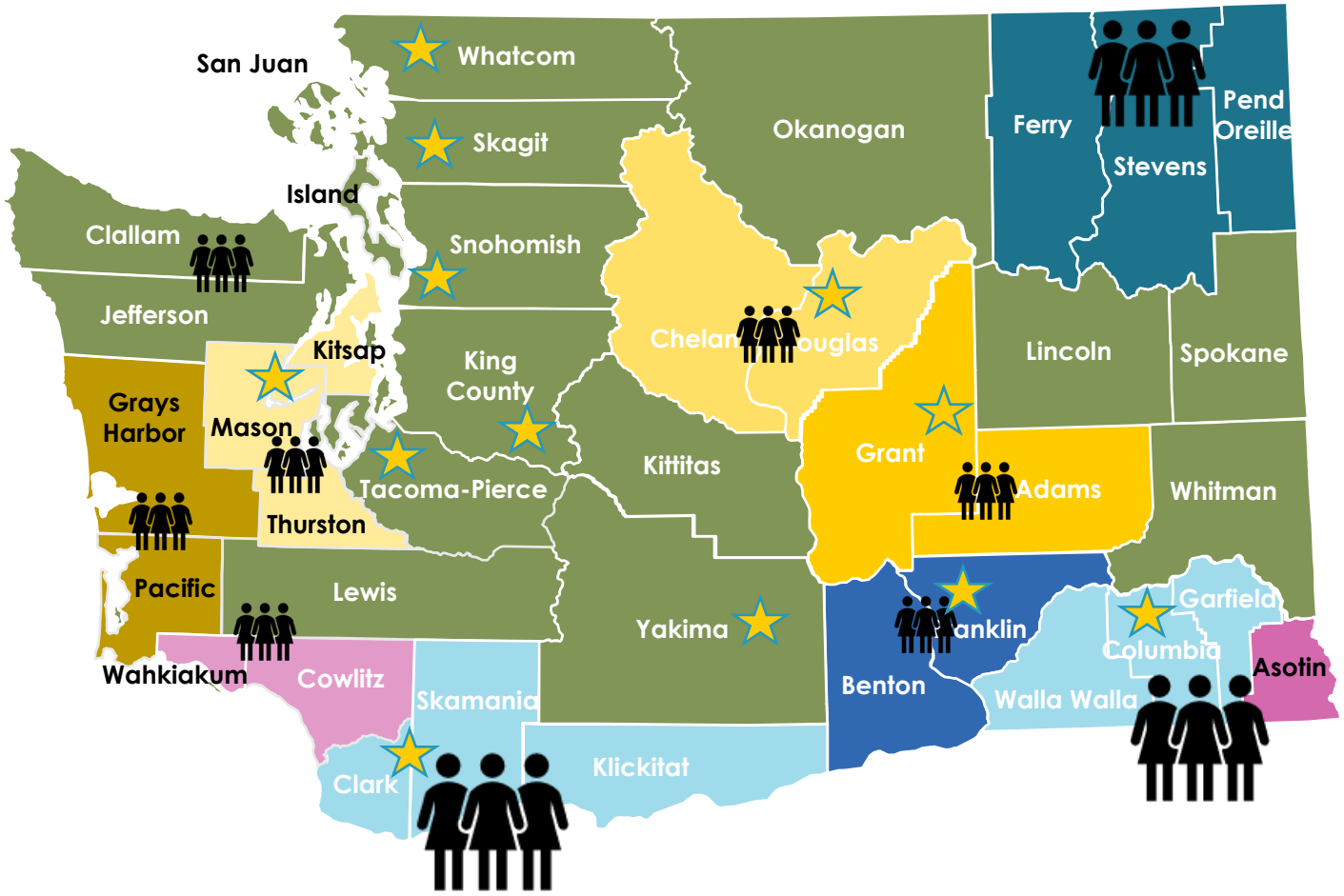
- Helping Parent matches
  - P2P program
  - T1D program
- Culturally and linguistically relevant groups
- SibShops

Community

- Seasonal and social events

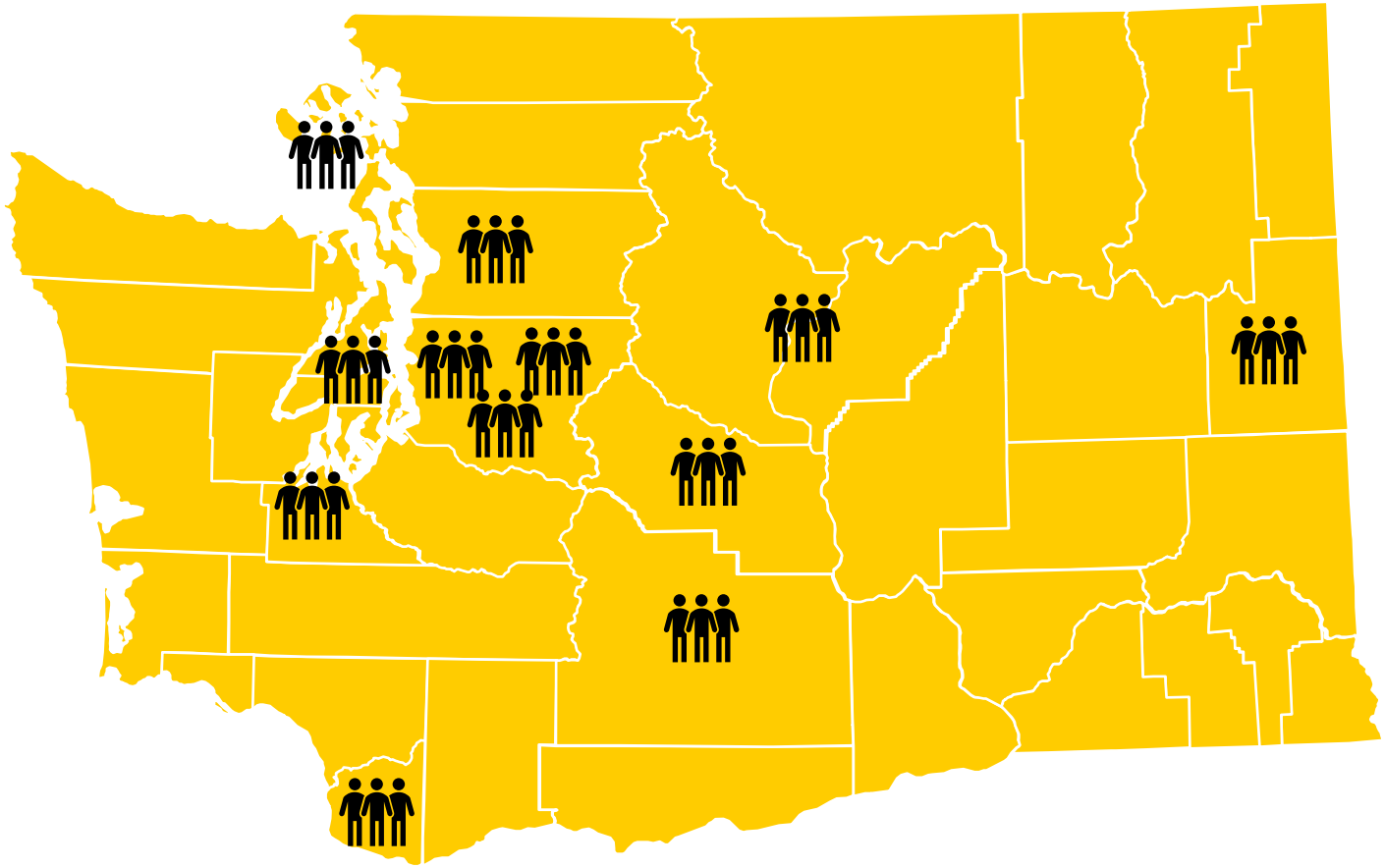
Training and Education on a variety of topics

Parent to Parent Chapters



- Single County P2P
- Multicounty P2P
- Multicultural P2P Coordinators

Fathers Network Chapters



Fathers Network Chapter

Family Engagement and Leadership

The **Washington Statewide Leadership Initiative** (**WSLI**) is a collaborative of family-serving organizations and state/local systems partners around the state focused on empowering families of CYSHCN to be active partners in their child's care, school, and life.

WSLI curates a bi-weekly bulletin to feature events, opportunities, and resources in a timely manner for family leaders and CYSHCN professionals in all areas of the state. To learn more about this collaborative and/or subscribe to the bulletin go here.

Family-led and serving organizations across the state:

- Parent to Parent – all CYSHCN families welcome, focus on I/DD
- Washington State Fathers Network – focus on fathers and male caregivers
- Washington State Community Connectors – focus on mental/behavioral health needs
- PAVE – all CYSHCN families welcome, TA center

Neurodevelopmental Centers of Excellence (NDC)

What is an NDC and What do they do?

An NDC is an agency that provides outreach, evaluation, diagnosis, treatment planning, and specialized therapies, such as occupational, physical, and speech therapy to children up to 20 years of age with special health care needs

How do they support CYSHCN work?

NDCs can provide improve care coordination and health system navigation as they have a variety of resources all in one place for families. Many focus on Birth to Three population.

Neurodevelopmental Centers of Excellence (NDC)

How do NDCs collaborate with CYSHCN Coordinators?

CYSHCN coordinators are an **essential** part of the "warm hand off" transition out of NDC ESIT services for families.

Coordinators can provide consultation and support to FRCs working with families within NDCs

Coordinators may also serve as an additional support to families if necessary while they are engaged with NDCs.

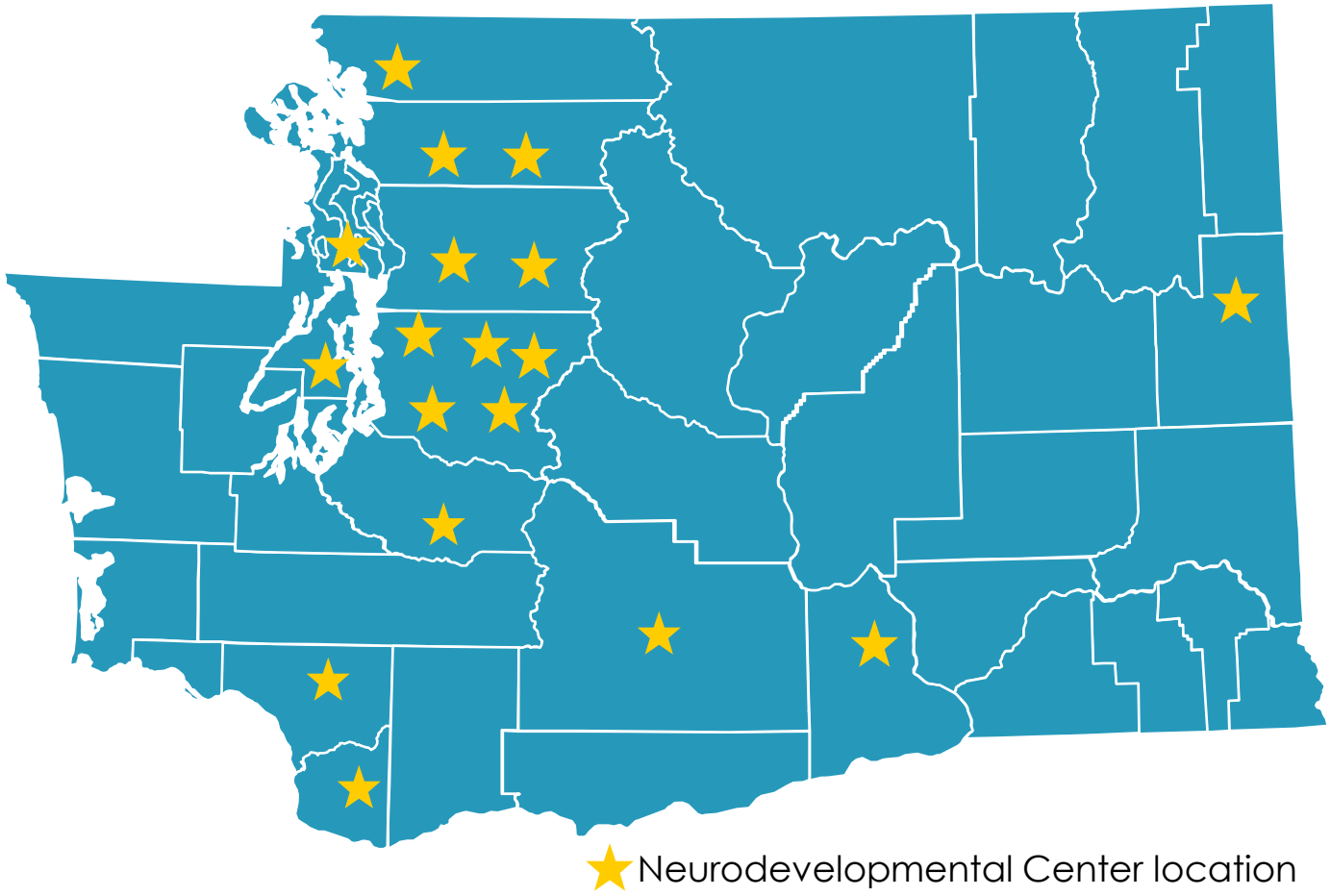
Coordinators can **refer** clients to NDCs when they identify a CYSHCN in need of additional care coordination, services, or support.

*Referrals can be made through direct communication

*Reach out to the NDC contract manager for connection to NDC partners

Amanda Simon (Process Improvement Coordinator)

Map of Neurodevelopmental Centers



Neurodevelopmental Centers (NDCs)

1. Birth to Three Developmental Center
2. Boyer Children's Clinic
3. Children's Developmental Center
4. Children's Therapy Center
5. ChildStrive
6. Encompass NW
7. Holly Ridge Center
8. Innovative Services NW
9. Joya Child and Family Development
10. Kindering Center
11. Mary Bridge Children's Therapy Services
12. PeaceHealth Children's Therapy
13. Progress Center
14. Providence Children's Center
15. Skagit Preschool and Resource Center (SPARC)
16. Skagit Valley Hospital, Children's Therapy Center
17. STEPS
18. Children's Village

Washington State Department of HEALTH

Maxillofacial Review Boards

Washington has 4 regional Maxillofacial Review Boards. The Washington State Department of Health (DOH) supports 3 of them through contracts to coordinate care for infants and children born with cleft lip and cleft palate. Maxillofacial Review Boards provide the interconnected critical care that children with cleft lip and cleft palate need. They ensure that providers plan and carry out the treatment in a coordinated, step-by-step manner as the child grows.

The structure and function of the boards conform to standards set by the American Cleft Palate-Craniofacial Association. They also help provide regional care consistent with medical homes. A medical home focuses on team-based care with the patient and family at the center. This model can be beneficial for individuals with disabilities and chronic health conditions. It is one of the key standards of care for children and youth with special health care needs.

Each Maxillofacial Review Board has a team of experienced and qualified professionals. A team coordinator oversees care for the children and their families and maintains the organizational structure of the review board.

- 3 Maxillofacial Review Board (MFRB) Cleft lip/palate contracts
  - Spokane
  - Tacoma
  - Yakima

Feeding Struggles Affect…

Over a million children nationwide are identified with severe feeding struggles. Thousands more go undiagnosed.

U.S. Census Data, 2010

Pediatric Feeding Disorder (PFD) impacts 1 in 37 children

HANDOUT FOR CAREGIVERS ON PEDIATRIC FEEDING DISORDER

Washington State Department of HEALTH

Quick Summary: Eating behaviors that used to be described as extreme picky eating, oral aversion, or sensory sensitivity, now has a formal name called **Pediatric Feeding Disorder (PFD)**.

PFD is defined as *impaired oral intake that is not age-appropriate, and is associated with medical, nutritional, feeding skill, and/or psychosocial dysfunction* [Goday 2019]. Children with feeding disorders often have complex medical or developmental differences that can lead them to have difficulty with eating and drinking.

When is PFD a concern?

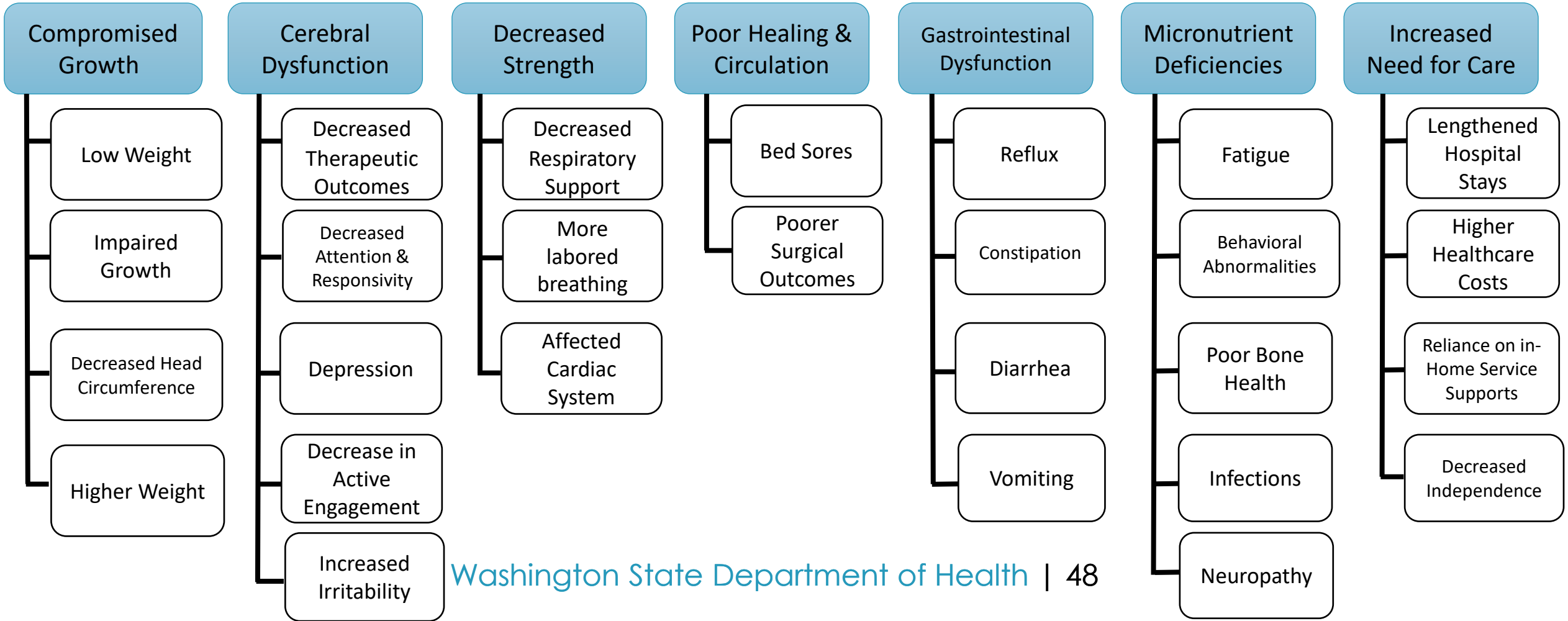
- When the feeding concern is lasting more than 2 weeks
- If your child is not meeting nutrition needs from diet
- If your child needs special accommodations to eat
- Your child's feeding is causing extreme stress or worry

Why are these children at higher risk for nutrition concerns?

- Disrupted parent-child feeding interactions
- Bowel management challenges
- Medication-nutrient interactions
- Special diets such a renal, diabetic, PKU
- Dental challenges impacting feeding/diet
- Use of complementary and integrative medicine (CAM) including supplements, alternative diets, megavitamins

Ptomey LT and Wittenbook W. Position of the Academy of Nutrition and Dietetics: Nutrition services for individuals with Intellectual and Developmental Disabilities and Special Healthcare Needs. J Acad Nutr Diet. 2015; 115:593-608

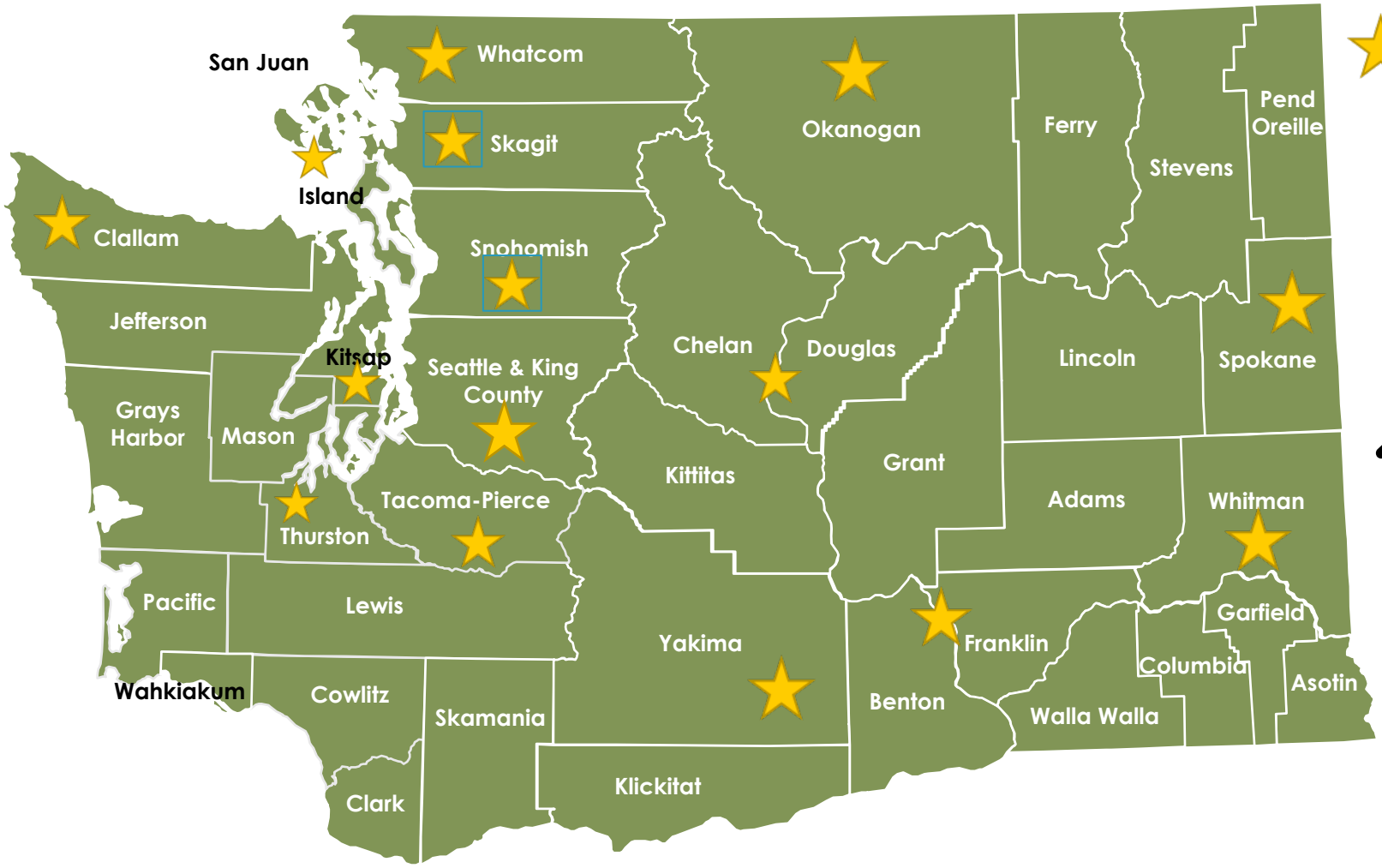
Consequences of Poor Nutrition in Individuals with Disabilities



What is Nutrition Network?

The CYSHCN Nutrition Network is a group of Registered Dietitian Nutritionists (RDNs) throughout Washington State who provide medical nutrition therapy (MNT) to children and youth with special health care needs. They represent a variety of employment settings, including local health departments, community clinics, hospitals, early intervention centers and home health agencies. In the early 1990's, feeding teams were created and partnered with the Nutrition Network.

Nutrition Network & Feeding Teams:



Feeding Teams

Total number of Feeding Teams: 33 and 403 total members

Nutrition Network:
293 total
249 active

T1D Workgroup Progress:

1. Designed a dedicated **Resource page**: Diagnosis: Diabetes - Family to Family Health Information Center (familyvoicesofwashington.org)

2. Established an **educational document for providers** to improve utilization of Managed Care Organizations (MCOs) benefits and services for children with Medicaid who have T1D.

3. Prioritized the revision of the ***Guidelines for Care of Students with Diabetes*** in partnership with the Office of Superintendent of Public Instruction (OSPI) to align with the American Diabetes Association's *Helping the Student with Diabetes Succeed: A Guide for School Personnel*

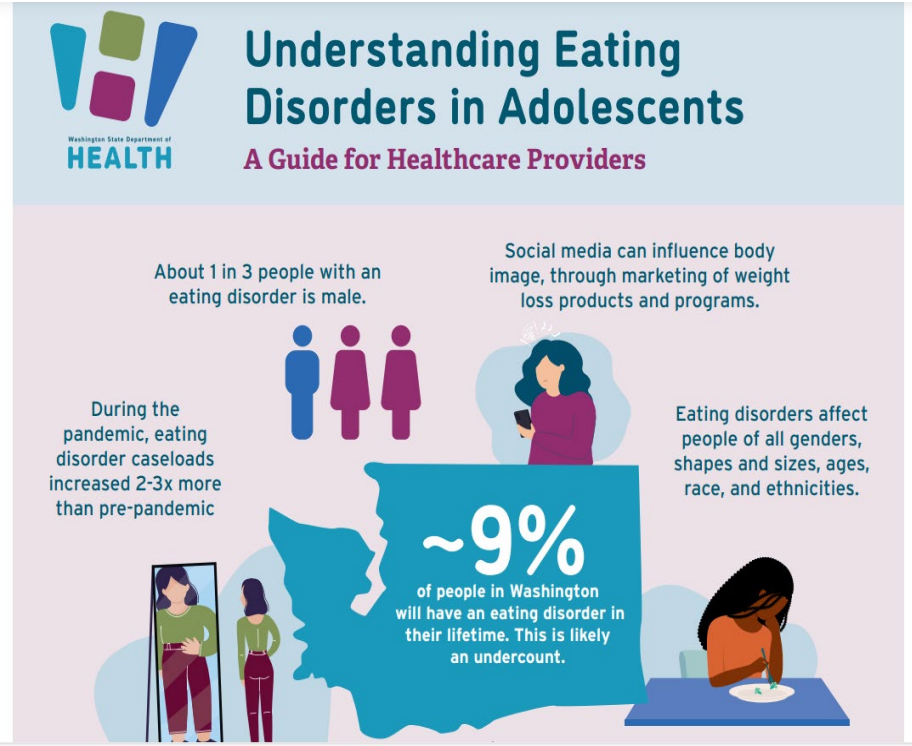
4. Created a T1D Statewide Coordinator role in partnership with PAVE and P2P and funded by Department of Health. A **T1D family support program** is underway

5. Began and continue providing ongoing support to a monthly virtual **T1D Teen Connect** support group lead by a2 young adult volunteers with T1D.

6. Developed an Eating Disorder handout for healthcare providers in WA State with mention of **Diabulimia**.

7. Based on a family feedback, we developed a simple, **1-page Fact Sheet (in English and 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.

Under **information** & Resources then scroll to bottom to **nutrition**



Behavioral Health and Adolescent Transition

Promote mental wellness and resilience through increased access to behavioral health and other support services.

- Take action to reduce stigma surrounding behavioral health, treatment and related challenges.
- Support interventions to address suicide ideation among CYSHCN.
- Identify opportunities to infuse trauma-informed care into working with CYSHCN.
- Identify and disseminate data for analysis on risk of suicide ideation for CYSHCN, including focus on youth with autism and other developmental disabilities.

Promote and facilitate successful transitions from pediatric to adult specialty services

Supporting Adolescents and Families Experiencing Suicidality (SAFES)

- DOH MCH (CYSHCN & Adolescent Health) awarded a 5-year HRSA Pediatric Mental Health Care Access Grant
- Partnership with Seattle Children's and Frontier Behavioral Health
- Focused on North Central and Better Health Together ACH Regions
- Increase their use of Children's Partnership Access Line (PAL)
- Train and support a crisis care team at Frontier Behavioral Health in Spokane - based on Seattle Children's Crisis Care Clinic
- In-person and telehealth crisis support services to clients with suicidality crises and inadequate current supports
- PAL will triage referrals from PCPs to the Frontier Crisis Care Team
- Supporting Adolescents and Families Experiencing Suicidality (SAFES)

Washington's Mental Health Referral Service for Children and Teens

- Connects patients and families with evidence-supported outpatient mental health services in their community.
- Free, telephone-based referral service funded by Washington Healthcare Authority and operated by Seattle Children's.
- Provides thorough mental health referrals for children and teens 17 and younger from across Washington.

Link:
PAL and WA Mental Health Referral Service for Children and Teens (seattlechildrens.org)

Phone number:
833-303-5437

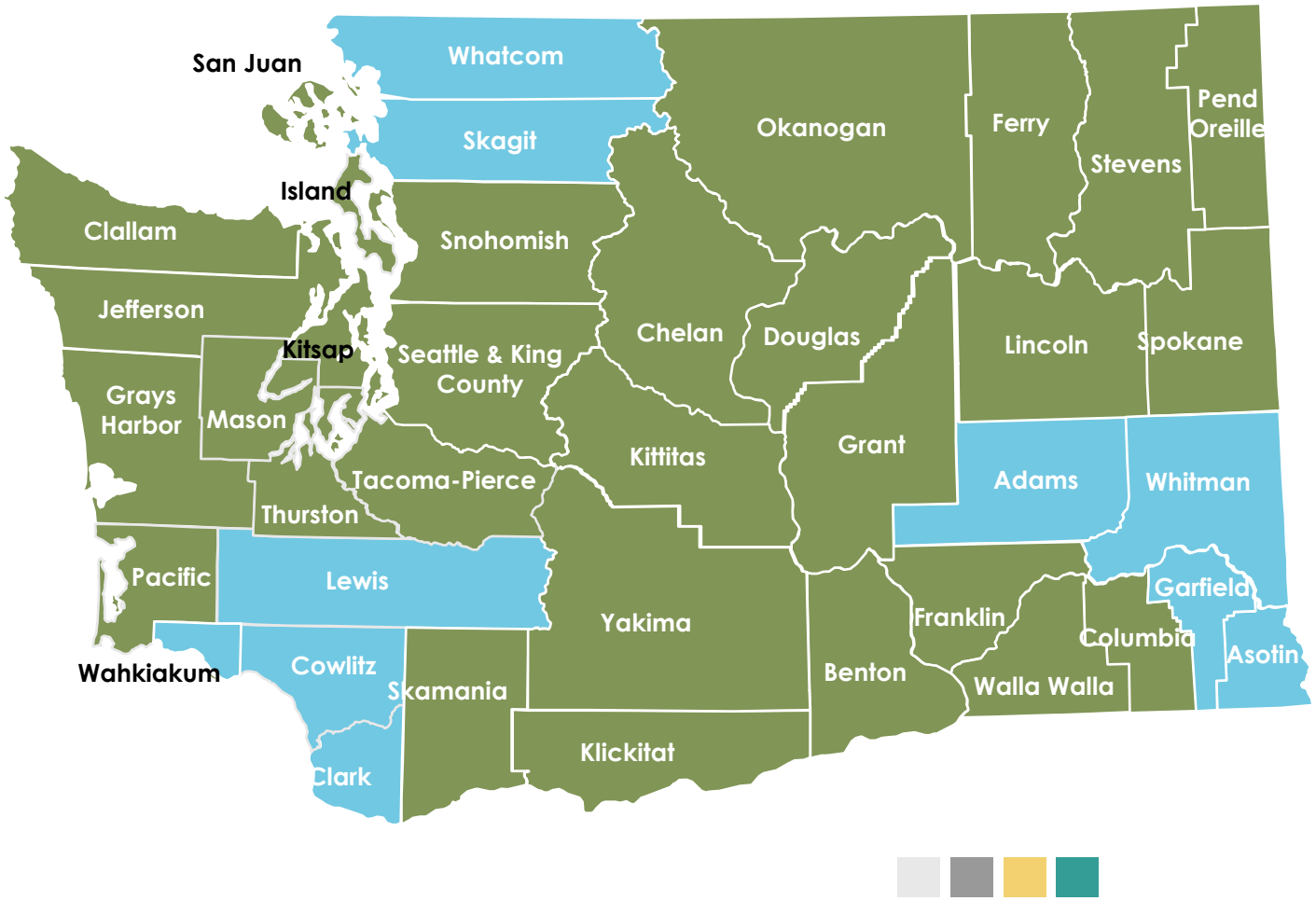
Online request form:
https://www.seattlechildrens.org/clinics/washington-mental-health-referral-service/family/referral-form/

Local Health Jurisdiction CYSHCN

- Knowledgeable about local services for CYSHCN and work on improving systems of care in their local areas
- Consult with CYSHCN service providers and other care coordinators
- Most offer care coordination services including supporting families with:
  - Access to care and services
  - Childcare/personal care/ respite
  - Emotional support and mental health - child and family - WA Mental health referral service
  - Housing*
  - Travel time /transportation
  - Accessing DDA services
  - Financial - basic needs, diapers, formula, single parents, having to leave work to care for child

Washington State Local Health Jurisdictions

- CYSHCN Care Coordination: Benton-Franklin, Chelan-Douglas, Clallam, Columbia, Grant, Grays Harbor, Island, Jefferson, Kitsap, Kittitas, Klickitat, Lincoln, Mason, NE Tri, Okanogan, Pacific, San Juan, Sea-King, Skamania, Snohomish, Spokane, Tacoma-Pierce, Thurston, Walla Walla, and Yakima



CYSHCN Care Coordination

Our goal:

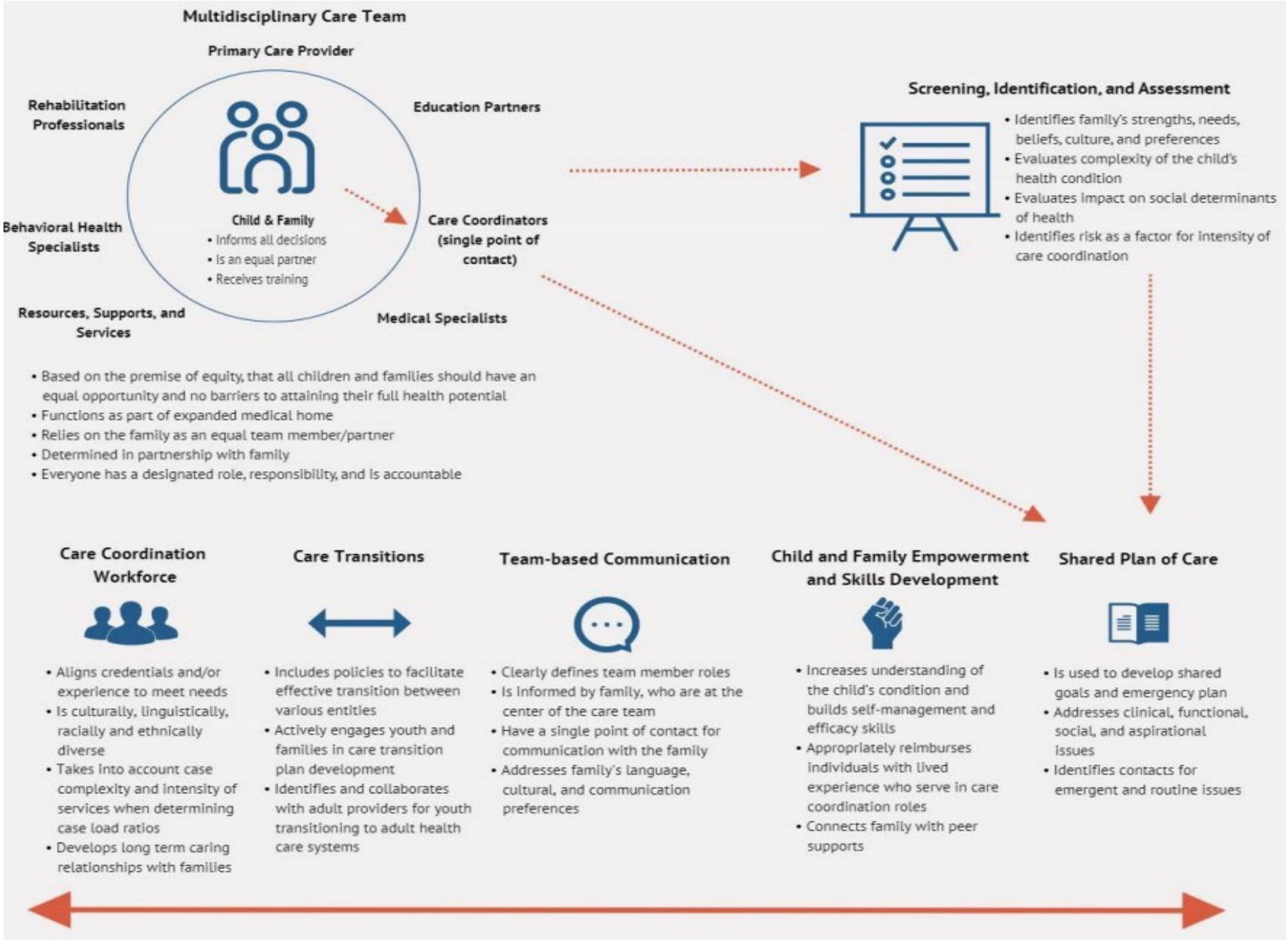
- Promote **family navigation**, and other family-centered **care coordination** models, to meet the complex needs of CYSHCN and their families, including health, socioeconomic, and psychosocial needs.

CYSHCN Care Coordination

Care Coordination Definition:

- patient- and family-centered, assessment-driven, team-based activities designed to meet the needs of children and youth.
- Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes, and efficient delivery of health-related services and resources within and across systems

National Care Coordination Standards



National Care Coordination Standards for Children and Youth with Special Health Care Needs (Oct. 2020)

Care Coordination Toolkit Overview

What is the Project?

Interactive Toolkit for Coordinators serving CYSHCN

How to Use the Care Coordination Toolkit

- Designed to work as both a **quick reference guide** as well as and **educational manual**
- Navigate through the **Table of Contents** so quickly find topics you would like support in.
- **Links are imbedded** throughout the document to make for easy navigation.

Table of Contents

Components of the Toolkit

There are Three Main Domains of the Toolkit

- Washington Systems of Care for CYSHCN
- Resource Referral Guide- Shared Plan of Care
- CYSHCN Life Course Transitions and Eligibilities

Washington Systems of Care for CYSHCN

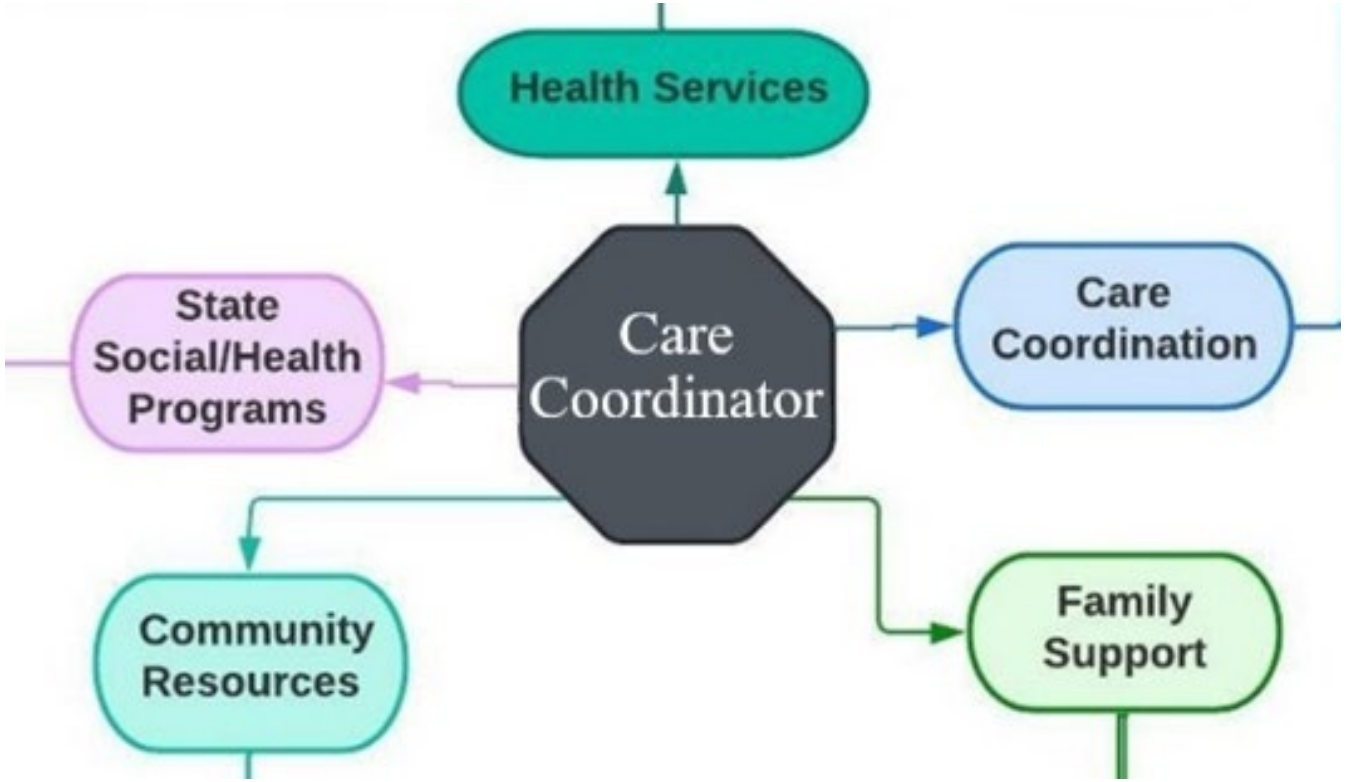
This is not an exhaustive list of CYSHCN connections but a foundational scaffolding of **existing** connections and resources available for CYSHCN

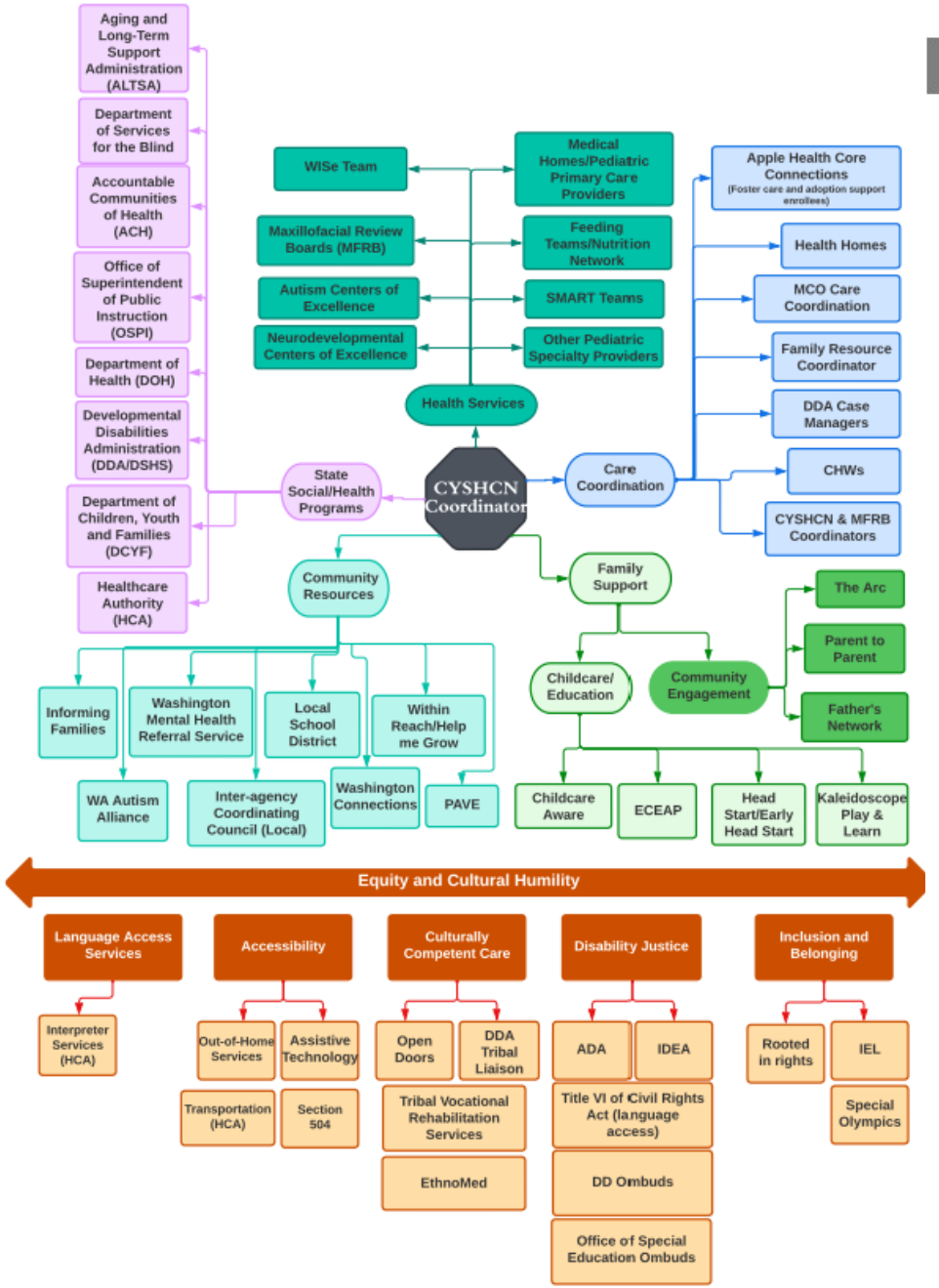
In the Toolkit the **Systems of Care Map** section contains descriptions of each map component with relevant **links** within the document and to outside resources

Users can navigate to the **Table of Contents** to quickly navigate to topics of interests

Washington Systems of Care for CYSHCN

Washington Systems of Care for CYSHCN





Acronym Key

CYSHCN: Children and youth with special Healthcare Needs

WISe-Wrap Around Intensive Services

SMART-School and Medical Autism Review Team

MCO-Managed Care Organization

DDA-Developmental Disabilities Administration

CHW-Community Health Worker

MFRB-Maxillofacial Review Board

ECEAP-Early Childhood Education and Assistance Program

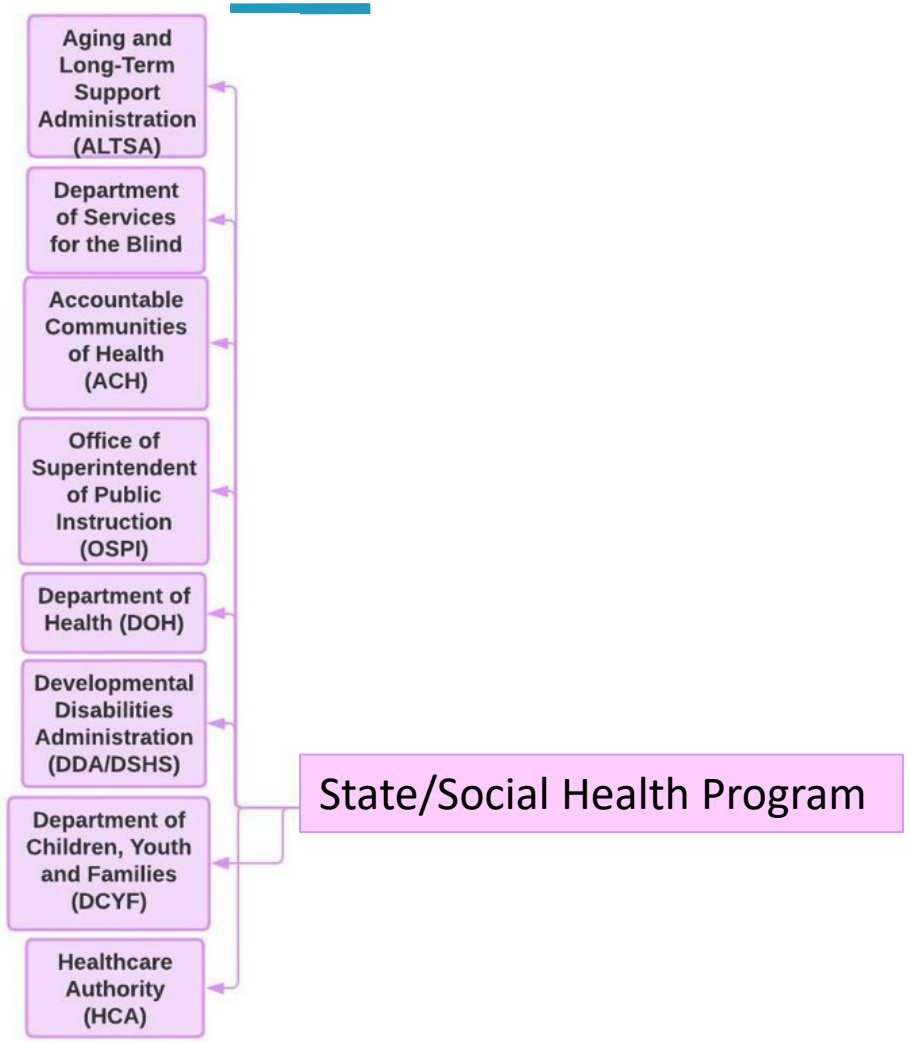
ADA-Americans with Disabilities Act

IDEA-Individuals with Disabilities Act

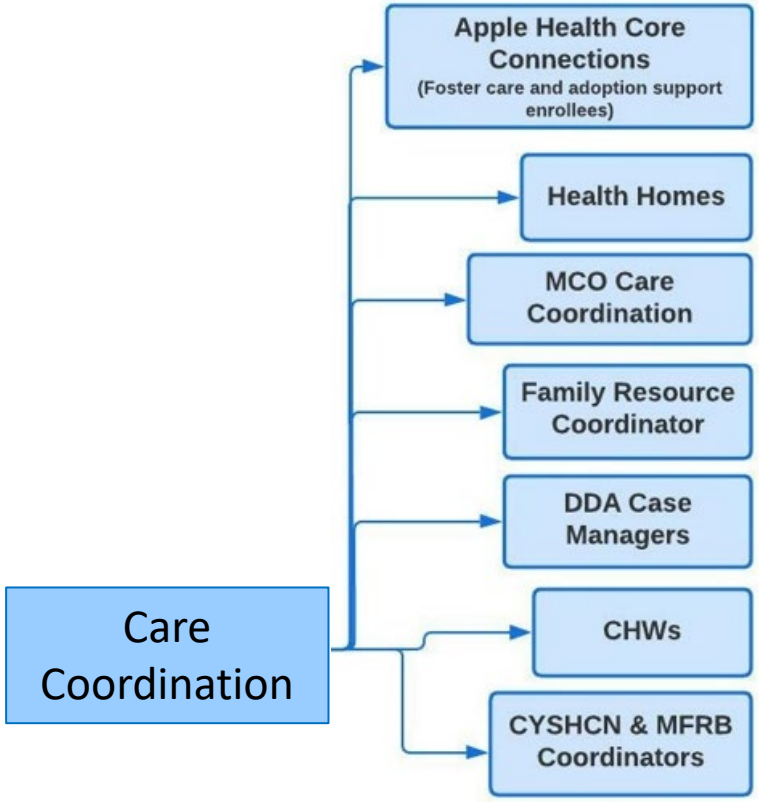
NCLD-National Center for Learning Disabilities

IEL-Institute for Educational leadership

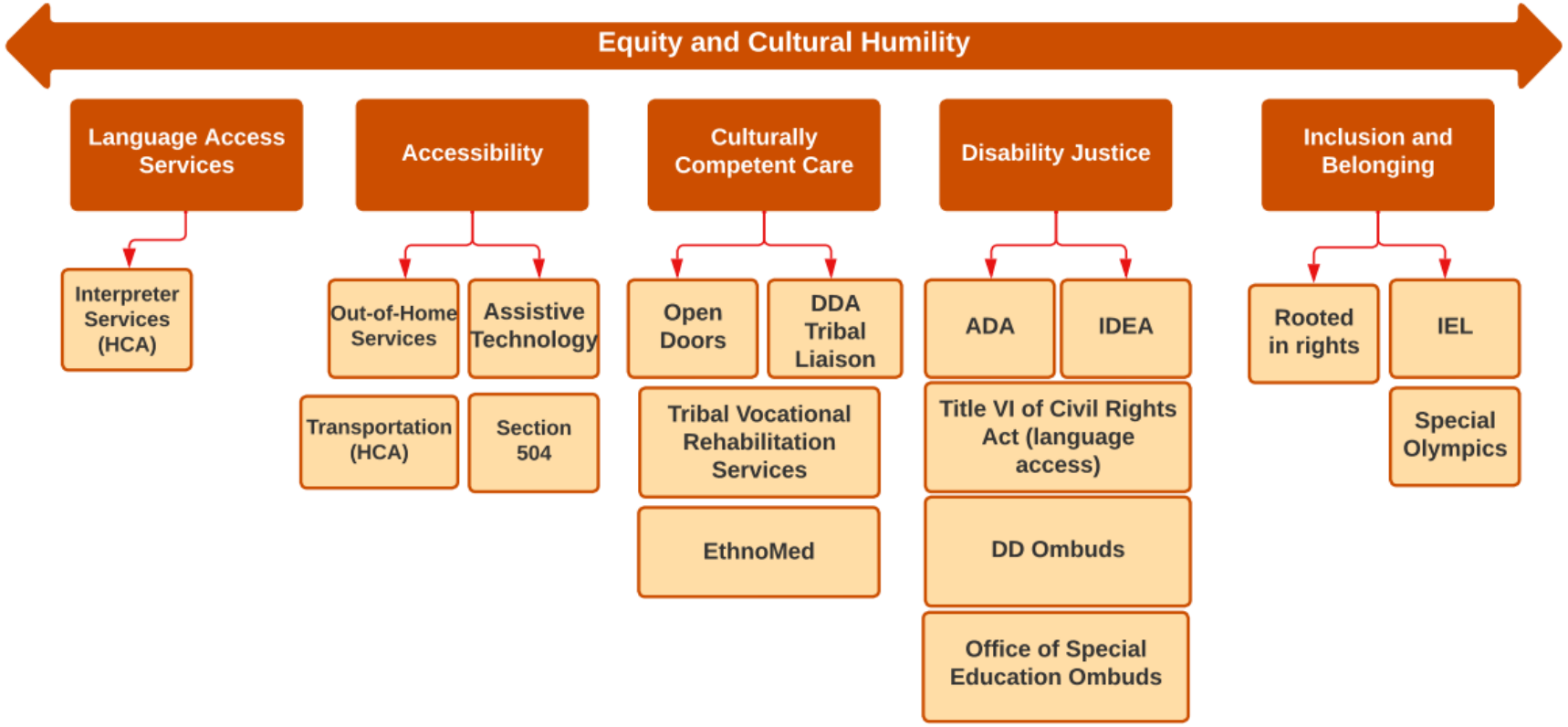
Washington Systems of Care for CYSHCN



Washington Systems of Care for CYSHCN



Washington Systems of Care for CYSHCN



Resource Referral Guide-Shared Plan of Care

This section of the Toolkit offers suggestions in **HOW** to engage with CYSHCN as well as resources that may be helpful.

How to Engage

Shared Plan of Care (SPoC)-Tool that allows CYSHCN and families to:

- Map out their goals
- Identify what **THEY** determine as **success**,
- And make a plan of **what they need** to reach their goals

The toolkit has several template **examples** of SPoC

(COIIN Birth to One Road Map, SPoC outline, Cue Cards, etc.)

Resource Referral Guide-Shared Plan of Care

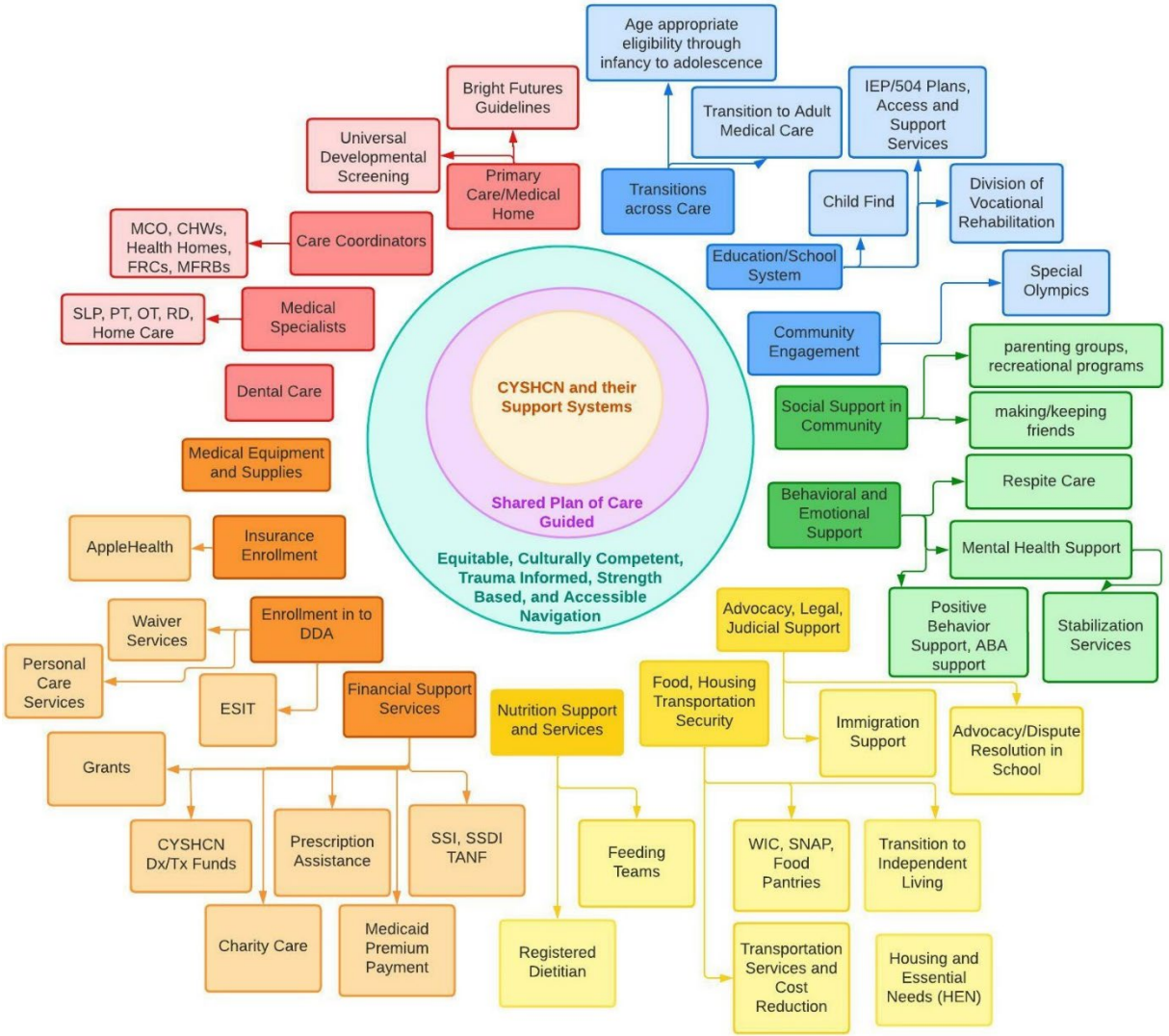
The Resources

Planned around supporting the **social and political determinants of health** CYSHCN may face

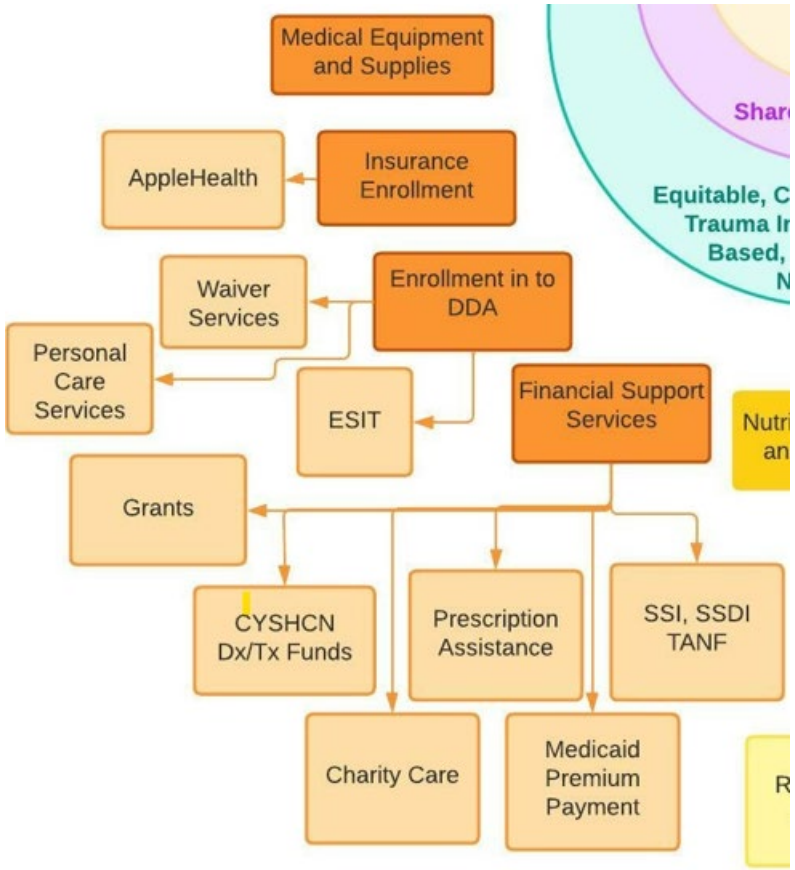
- Not exhaustive list, but could be helpful prompts when working with SPoC
- Toolkit has **resources and notes associated** with different themes in **pages 33-34**

AREAS OF SUPPORT	RESOURCES	NOTES
PRIMARY CARE/MEDICAL HOME	Bright Futures Guidelines SMART Teams Autism Center of Excellence In your County	
MEDICAL SPECIALISTS		
DENTAL CARE	Finding Dental Care Special Needs Dentistry	
MEDICAL EQUIPMENT	DME CYSHCN Dx/Tx-pg. 25 Assistive Technology	
INSURANCE ENROLLMENT	Apply for Apple Health Washington Health Plan Finder	

Resource Referral Guide-Shared Plan of Care



Resource Referral Guide-Shared Plan of Care



Resource Referral Guide-Shared Plan of Care

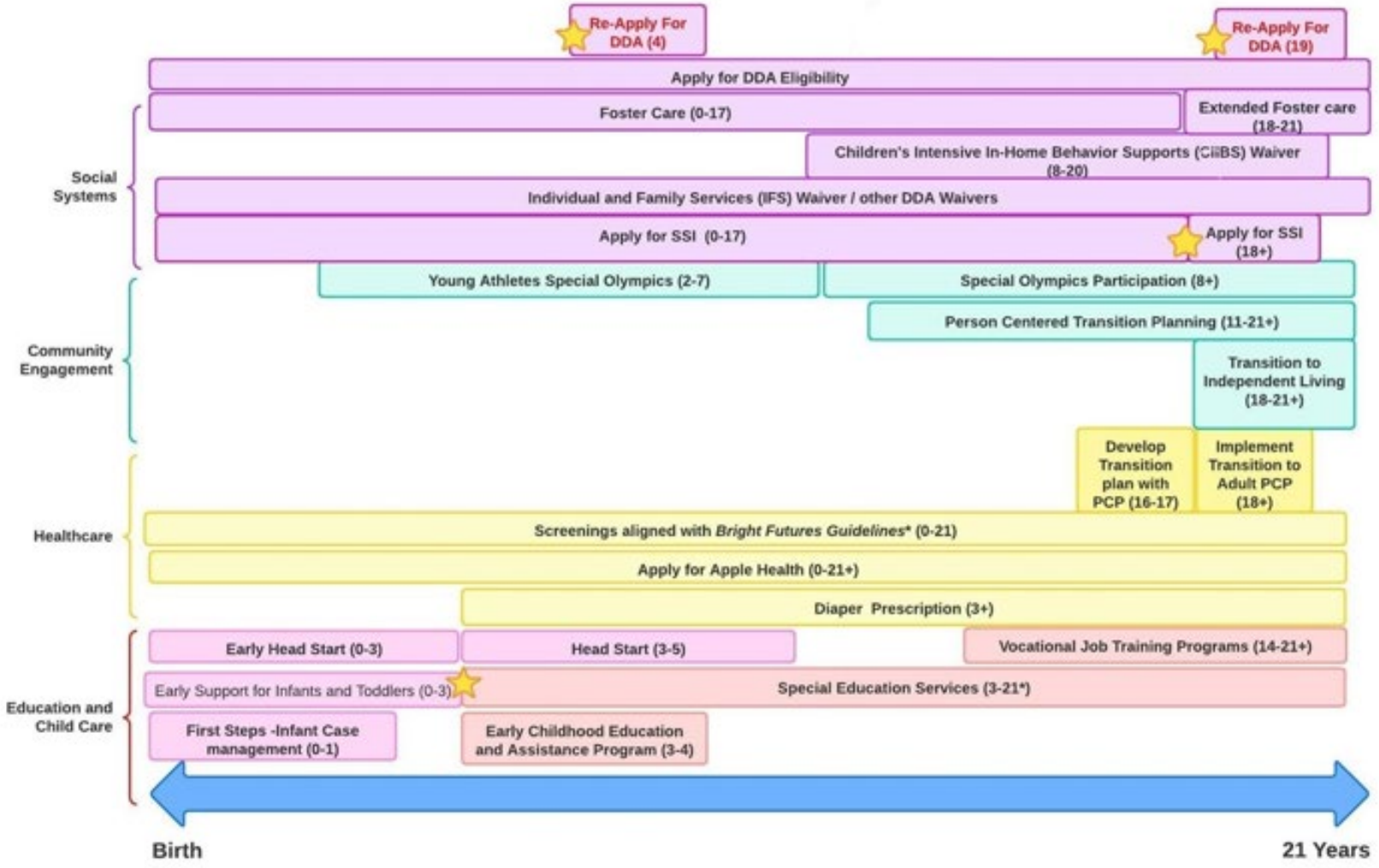
MEDICAL EQUIPMENT	DME CYSHCN Dx/Tx-pg 25 Assistive Technology	
INSURANCE ENROLLMENT	Apply for Apple Health Washington Health Plan Finder	
ENROLLMENT INTO DDA	**DDA Application and Eligibility*** DDA Eligibility and Service Guide How to Apply for DDA Services in Washington State DDA Eligibility and Service and Information Request Early Childhood Transitions and DDA Role	
FINANCIAL SERVICES	Ben's Fund UHCCF Medical Grant Prescription Assistance-NeedyMeds Washington Autism Alliance Grants Medicare Reimbursement Program Apple Health Premium Program Seattle Children's Financial Assistance Sacred Heart Hospital Patient Financial Assistance MultiCare Financial Assistance Social Security Income Application	Charity Care and Financial Assistance may sometimes be used interchangeably in hospitals. CYSHCN can reach out to their hospital's charity care program for information on eligibility and application.

CYSHCN Life Course Transitions

There are a variety of age specific services and enrollment periods available to CYSHCN, but keeping track of them all can be challenging.

- Map is a quick reference point on upcoming enrollment and transition opportunities
- Toolkit has associated resources and guidance for each section
- Three crucial transition and enrollment periods to know of:
  1. Applying for DDA (age 4, and 19*)
  2. Applying for SSI
  3. Ensuring a warm hand off from ESIT to Special Education and/or CYSHCN Coordinator (age 3-4)

CYSHCN Life Course Transitions



CYSHCN Life Course Transitions

AREAS OF TRANSITION	RESOURCES	GUIDANCE
DDA APPLICATION AND ELIGIBILITY ★	DDA Eligibility and Service Guide Applying for DDA Services in WA DDA Eligibility Early Childhood Transitions	CYSHCN who have DDA services lose that access through an **expiration on their 4th birthday**. They need to reapply for eligibility to continue past four. The same is true for CYSHCN have DDA eligibility prior to age 10. CYSHCN **loose eligibility on their 10th birthday** through an expiration **IF** they were determined eligible prior to age 10 under a **developmental delay** diagnosis. They will need to reapply for eligibility past age 10. CYSHCN who are DDA eligible **prior to age 19** will need to have a **review** for continued eligibility if their last determination was before age 16. A **review** for continued eligibility is necessary on a CYSHCN client's **20ths birthday** if their eligibility determination was based on academic delays in Broad Reading and Broad Mathematics IMPORTANT: Once a CYSHCN client is determined to be DDA eligible, they need to **Request Services** by making a Service and Information Request to access services such as CIIBS, Case management, Personal Care assistance (Community First Choice Program).
CHILDREN'S INTENSIVE IN-HOME BEHAVIORAL SUPPORT (CIIBS) WAIVER, INDIVIDUAL AND FAMILY (IFS) SERVICES WAIVER, OTHER DDA WAIVERS	CIIBS FAQ DDA Eligibility and Service Guide CIIBS Waiver IFS Waiver	There are 5 DDA waivers (Individual and Family Services, **CIIBS**, Basic Plus, Core and Community Protection). CYSHCN may only be on one wavier at a time. CIIBS is available for those **8-20 years of age**. See page 10 in the DDA Eligibility and Service guide for additional waiver information. IFS waiver may be more accessible to receive than CIIBS and families can qualify before the age of 8. Both IFS and CIIBS support assistive technology requests and accommodations.

Contact Information

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Communications and Early Childhood – Main point of contact
Linda Ramirez, linda.ramirez@doh.wa.gov

Process Improvement – Contact for CHIF and NDCs, Systems CoP
Amanda Simon, Amanda.Simon@doh.wa.gov

Nutrition Consultant – Contact for nutrition, T1D Workgroup, MFRB, and Dx/Tx
Khim Schoenacker, Khimberly.Schoenacker@doh.wa.gov

Family Engagement Consultant – Contact for Family Engagement and FESAT
Nikki Dyer, Nikki.dyer@doh.wa.gov

Inbox for Family/Partner Referral Questions: CYSHCN@doh.wa.gov

Partners and Referral Sources

- Neurodevelopmental centers
  - https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/HealthandSafety/ChildrenwithSpecialHealthCareNeeds/Partners/NeurodevelopmentalCenters
- Maxillofacial Review Boards – care for Cleft Lip/Palate
  - https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/HealthandSafety/ChildrenwithSpecialHealthCareNeeds/Partners/MaxillofacialTeams
- DOH Newborn Screening Program
  - https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/NewbornScreening
- Early Support for Infants and Toddlers (ESIT)
  - https://www.dcyf.wa.gov/services/child-development-supports/esit

Resources

National Standards of Care for CYSHCN

https://amchp.org/resources/standards-for-systems-of-care-for-children-and-youth-with-special-health-care-needs-version-2-0/

Tips for Providers Implementing National Standards

http://www.amchp.org/programsandtopics/CYSHCN/projects/NationalStandards/Documents/ProvidersTipSheet-NationalCYSHCNStandards.pdf

Updated Care Coordination Standards

https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/

Resources

UW Medical Home Partnerships Project

https://medicalhome.org/

PAVE

https://wapave.org/pave-programs/

Father's Network

https://fathersnetwork.org/

Parent to Parent

https://arcwa.org/parent-to-parent/map/

Washington Statewide Leadership Initiative

https://wslicoalition.org/

UW CYSHCN Nutrition Resource:

http://depts.washington.edu/cshcnnut/nutserv/index.html

Questions?

Washington State Department of HEALTH

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