Children and Youth with Special Healthcare Needs
Care Coordination Toolkit

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Land and Labor Acknowledgement

The Washington State Department of Health Children and Youth with Special Health Care Needs (CYSHCN) program recognizes and honors the original occupants and stewards of the land where we all individually and collectively gather. The writer of this toolkit is occupying space from lands of the traditional home of the Coast Salish people, the traditional home of all tribes and bands within the Duwamish, Suquamish, Tulalip, and Muckleshoot nations.

The CYSHCN program honors the survival, the adaptations, the forced assimilation, and the resilience and creativity of Native peoples—past, present, and future. We encourage CYSHCN partners to consider their responsibilities to the people and land, both here and elsewhere, and to stand in solidarity with Native, Indigenous, and First Nations People, and their sovereignty, cultural heritage, and lives.

We also recognize and acknowledge the labor upon which our country, state, and institutions are built.

We remember that our country is built on the labor of enslaved people who were kidnapped and brought to the U.S. from the African continent and recognize the continued contribution of their survivors. We also acknowledge all immigrant labor, including voluntary, involuntary, trafficked, forced, and undocumented peoples who contributed to the building of the country and continue to serve within our labor force. We acknowledge all unpaid caregiving labor.

To the people who contributed this immeasurable work and their descendants, we acknowledge their indelible mark on the space in which we gather today. It is our collective responsibility to critically interrogate these histories, to repair harm, and to honor, protect, and sustain this land.

**This land acknowledgement is adapted from Seattle Colleges*

How to use this Toolkit

The intention of the Children and Youth with Special Health Care Needs (CYSHCN) Care Coordination Toolkit is to provide care coordinators a comprehensive consolidation of resources and guidance across the various systems of care available to CYSHCN in Washington state. Care coordinators may reference this document quickly by navigating to the table of contents and selecting the resource or topic of interest they would like support in. There are three main components of this toolkit: Washington Systems of Care for CYSHCN, Shared Plan of Care: Resource Referral Guide, and CYSHCN Life Course Transitions and Eligibilities. Care Coordinators will find a reference map in each section that can be used to navigate the intersecting and overlapping nature of various services, resources, and agencies. The **Systems of Care** section provides thorough descriptions of pertinent CYSHCN agencies and programs, while the **Shared Plan of Care: Resource Referral Guide** and the **Life Course Transitions and Eligibilities** sections offer initial grounding guidance followed by tables with consolidated and organized resources for quick reference.

This guide is geared to support the needs of care coordinators and the CYSHCN clients that they serve, but it is also available for distribution to other pertinent CYSHCN partners and families.

Children and Youth with Special Health Care Needs

In this document, we use Children and Youth with Special Health Care Needs or CYSHCN to describe our key audience and the program at the Department of Health. Each Care Coordinator may use different age ranges, disabilities or diagnoses, or other criteria to guide which populations they serve.

CYSHCN have or are at increased risk for developing ongoing physical, developmental, behavioral, or emotional conditions. They also require health and related services of a type or amount beyond that required by children generally. CYSHCN includes all individuals between the ages of 0 to 18, and sometimes up to 21.[1]

1 in 5 or 20% of children in Washington state have special health care needs.

A note about using "CYSHCN": Children and Youth with Special Health Care Needs is not strengths-based or preferred language. As we discuss below, "Special needs" is not respectful when talking to or about an individual child or youth and their family. We use CYSHCN in this toolkit as it is a federally recognized designation and broad enough to encompass the range of children, youth, and families our partners work with. There is a movement to shift away from this term to be more inclusive. However, as it is a federal term, it will take time to bring the change. We will update this toolkit as necessary to reflect any shift in language.

Family Engagement

It is important to recognize that children and youth live within a family structure. They often rely on their family for caregiving support, housing, food, and other socioeconomic and emotional supports. Families are the primary experts on their child's health, and all care should be centered on the child and family's needs and well-being.

A family is a group of two or more chosen individuals who identify as a family, including formal and informal caregivers of CYSHCN.

The CYSHCN team at DOH is committed to engaging families and youth in leadership roles, program development, and evaluation. Advancing the system of care for CYSHCN requires leadership, active partnership, persistence, and the coming together of family and other invested partners. Family engagement is an ongoing process that should allow families and programs to thrive. Equitable family engagement is the intentional partnering of children, youth, and families at all levels across systems involved in providing care and services.

Care Coordination

Care Coordination is "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."[2]

Evidence[3-24] demonstrates that CYSHCN and their families benefit greatly from wrap-around support and services. Wrap-around supports ensure their child has access to the services and resources they need to:

- Develop and realize their potential
- Satisfy their needs
- Build capacities to interact successfully with their biological, physical, and social environments

A single Care Coordinator or multiple coordinators across different programs with whom a family interacts can together provide the needed support. However, most families coordinate care on their own which can result in financial hardship, emotional distress, and incomplete or missing care.

The Blueprint for Change for CYSHCN is a national framework to improve the system of services for CYSHCN. The goal is to help them "enjoy a full life and thrive in their community from childhood through adulthood.[25]" The Blueprint has four key parts: access to services, financial support for services, health equity, and quality of life and well-being. Care Coordination services actively work to promote the quality of life and well-being for a child and their family while addressing the other three parts.

The National Care Coordination Standards for CYSHCN outline and promote high-quality Care Coordination as an important service for CYSHCN and their families[2]. These standards are part of federal and state efforts to improve the system and quality of care for CYSHCN and their families.

Warm Hand-Offs and Referrals

A warm hand off is when two service providers working with one child connect before the child or CYSHCN transitions out of a service. This practice allows service providers to plan with each other and the CYSHCN's family to plan better for the next steps, including any needed resources and supports. This critical connection is essential to improve the quality of care for CYSHCN in our state.

Without this "warm hand off" CYSHCN and their support systems are often not aware of the available services after they transitioning out of a resource. This can lead to CYSHCN falling into the "cracks" of care. Not being part of the systems of care while a CYSHCN still has a need harms their physical and social health.

Referral Recommendations

There is no right or wrong mechanism to consider when working with a referral, but there are several factors to keep in mind:

- **Make a plan to connect with CYSHCN families.** Start **early and often** to connect families with their CYSHCN Coordinator. As a first step, you can share the CYSHCN Program Brochure with families, which is available in 16 languages.

- **Connect with the Family Resource Coordinator (FRC) at your local Early Support for Infants and Toddlers (ESIT) Program.** FRCs will be familiar with the clients who are close to aging out of their service, and they can help facilitate warm hand offs between families and local CSYHCN Coordinators. You can refer to and find an FRC through the ESIT Referral Contacts by County and School District.
    - Warm Hand Off Example:
        - **Six months before** a child ages out of Early Support for Infants and Toddlers (ESIT), the Family Resource Coordinator (FRC) can reach out to their local CYSHCN Coordinator if the communication connection has been made. The CYSHCN Coordinator can ask the FRC to share resources with the family and

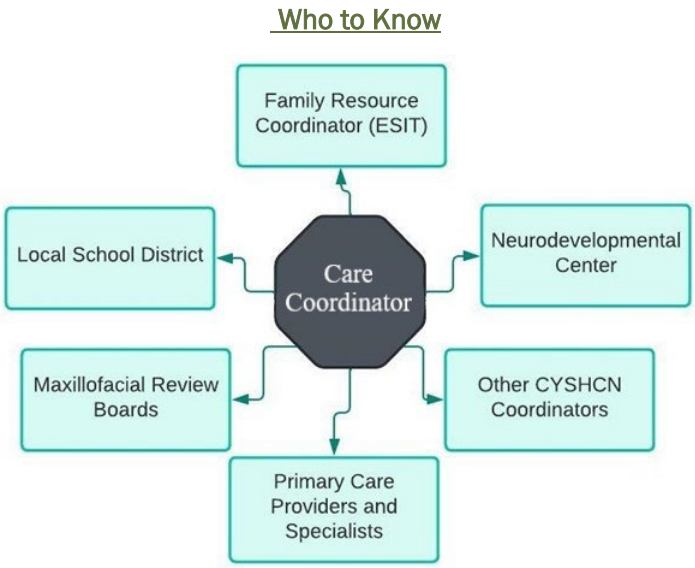
offer guidance on how a CSYCHN Coordinator may support them and how they can get in touch.

- **2-3 months before** a family's ESIT services end, FRCs and CYSHCN Coordinators may plan to directly connect with families aging out of services. During this time, you can use the Shared Plan of Care to connect with CYSHCN and their families. This can help identify what success may look like for each child. You can also use this plan to connect families to the necessary resources to work towards that success.

- **Release of information form.** You are required to share a "release of information form" if you would like to disclose the CYSHCN's personal information when reaching out to a new service provider. This is a required step before sharing any personal information between two referral points of contact.

- **Never frame a CYSHCN connection as required**. Often CYSHCN and their support systems experience overwhelm and may feel burnt-out. Although your role is to support your clients, sometimes clients may not be ready for more connections. This is absolutely **okay** and should be honored. It aligns with trauma informed care and healing centered engagement approaches. Healing Centered Engagement empowers clients to make their own choices. Clients are not required to enroll and access a CYSHCN Coordinator's support. They know the service exists and can reach out when they are ready.

The following map is an example of important connection points and referrals. You may frequently connect your clients to these referrals to ensure their continuity of care.



Inclusive and Trauma Informed Care for CYSHCN

It is essential to engage with CYSHCN and their families in a trauma informed and inclusive way. A key reason is to continue to foster a safe space for health, healing, and trust building between CYSHCN and the systems of care they interact with.

Many CYSHCN and their families go through at least one trauma in their experience with systems of care. They may also be retraumatized depending on their previous experiences. Your role exists within an intersection of **support, advocacy, and education** for CYSHCN clients and systems. You can support your client's health and help build new positive and trusting associations with the health system through what is referred to as **Corrective Emotional Experiences (CEE)**. CEE are when clients are able to build new positive and trusting associations with the health system after previously experiencing a trauma in their health system interaction.

The CYSHCN program at DOH encourages all Care Coordinators to know and use trauma informed and inclusive care principles. Each of these topics contain a rich pool of researched evidence and guidance for successful intervention. In this toolkit, we cover the basics and provide you with resources for further research and education.

Trauma Informed Care (TIC)

There are four "R's" that form the foundation of a Trauma Informed Care (TIC) mindset. This mindset **realizes** the impact of trauma, **recognizes** the trauma signs and symptoms, **responds** to its existence through policies and practices, and **resists** re-traumatization. In practice, the TIC mindset varies depending on the role of the practitioner.

It is important to be mindful that true trauma informed care and being **anti-racist** are interconnected. You cannot be trauma informed without also being anti-racist. This intersectionality is essential to a TIC framework and mindset. Education and research of the two is necessary to foster a safe and inclusive space for CYSHCN.

Impactful TIC requires both a **skillset** of tools for intervention and the **mindset** and framing of how to engage with clients. Tangible CYSHCN specific tools of the 4 R's include:

- Using inclusive, culturally, and individually responsive language, and
- Creating materials that empower families.

Use **strengths-based** framing and language to implement TIC and best benefit CYSHCN and their families instead of a deficit-based language. This approach is also called Healing Centered Engagement and seeks to advance a collective view of healing from the family and CYSHCN system as a whole.

Here are a few examples in practice:

- Engage and empower CYSHCN and their families by highlighting what they are proud of and the assets they use in their care and support.
- Avoid negative or pity-based language, even if it is intended to support your client.
- Avoid defining clients by their trauma, medical condition, or their history.
- When offering support consider not just individual barriers or trauma experiences in CYSHCN care but also **adverse community environments.** These can include poverty, discrimination, poor housing quality, violence, or community disruption. Identifying these barriers can help develop trust, collective understanding, empathy, support resource allocation and reduce or remove identified barriers.
- **Do not use the term "non-compliant"** when clients do not follow suggested advice. If your clients don't follow your direction or advice, use it is as a learning opportunity. Ask CYSHCN and their families **what they need and how they need it** to identify what

works best for them. If your initial direction or advice doesn't align with their needs, you can adjust and reframe accordingly.

- Position yourself so that you are at eye level with the CYSHCN, when possible.

Inclusive Language

Intentional and inclusive language choice is particularly important for this population. Using offensive and disempowering terms can traumatize or re-traumatize clients. Avoid common colloquial terms such as “crippled”, “differently-abled”, or “crazy”.

It is important to recognize that there is no monolithic language style preference across the disability community. The two major linguistic preferences are person-first language and identify-first language.

Person-first language is framed as “People with disability.” It is reduces the dehumanization of disability and is CDC recommended. Person-first language emphasizes the person *first* and not the disability.

Identity first language is framed as “Disabled people.” It celebrates disability pride and identity. The Autistic and Deaf or Hard of Hearing advocacy communities have championed this language.

The best practice to make sure you’re using inclusive language is to simply ask CYSHCN and their families for their preference. You may feel uncomfortable at first asking for self-identifying preferences. But shying away from acknowledgement can indirectly reinforce the incorrect bias of shame and stigma associated with disability. Asking and acknowledging preference also aligns with Healing Centered Engagement, which recognizes each CYSHCN’s diverse needs and preferences.

If you would like more information around specific language on what to avoid or what can be used instead, please see a detailed fact sheet that offers TIC alternatives in the Inclusive Language section of the Appendix.

Additional Trauma Informed Care Resources

PDF-Trauma-Informed-Approaches.pdf (nastad.org)

GUCCHD - Trauma-Informed Care (georgetown.edu)

The Future of Healing: Shifting From Trauma Informed Care to Healing Centered Engagement | by Shawn Ginwright | Medium

Washington Systems of Care for CYSHCN

How to Use the CYSHCN System referral Map

Care Coordinators often juggle many different responsibilities within their agency. To support efficiency and prevent duplication of efforts, we have created a Systems of Care map. This map will support Care Coordinators in building networks and referral pathways for clients.

The map below is not an exhaustive list of connections, but a foundational scaffolding of necessary connections and existing resources for CYSHCN and their families in Washington state. We encourage connections between LHJs and other Care Coordinators and resource and service partners. Building these connections can be helpful when referring families to outside agencies and other Care Coordinators or partners. Send referrals depending on the family's requests and needs.

Before navigating the map, we recommend that you meet with the CYSHCN and their family to complete a Shared Plan of Care (SPoC). This tool empowers and supports families by helping them map out their CYSHCN's goals. A SPoC can help them identify their unique successes and provide a clear plan towards reaching their goals. You can use the **SPoC** to navigate the referral map below and better align with a CYSHCN and their family's goals.

The **SPoC** often contains:

- the child's goals and plans to achieve them,
- the child's medical conditions,
- what to do if a crisis occurs, and
- information about the child's family and important people in their life.

COIIN Birth to one Roadmap

COIIN Birth to one Roadmap- Spanish

Shared Plan of Care (SPoC)

CYSHCN Systems of Care Map

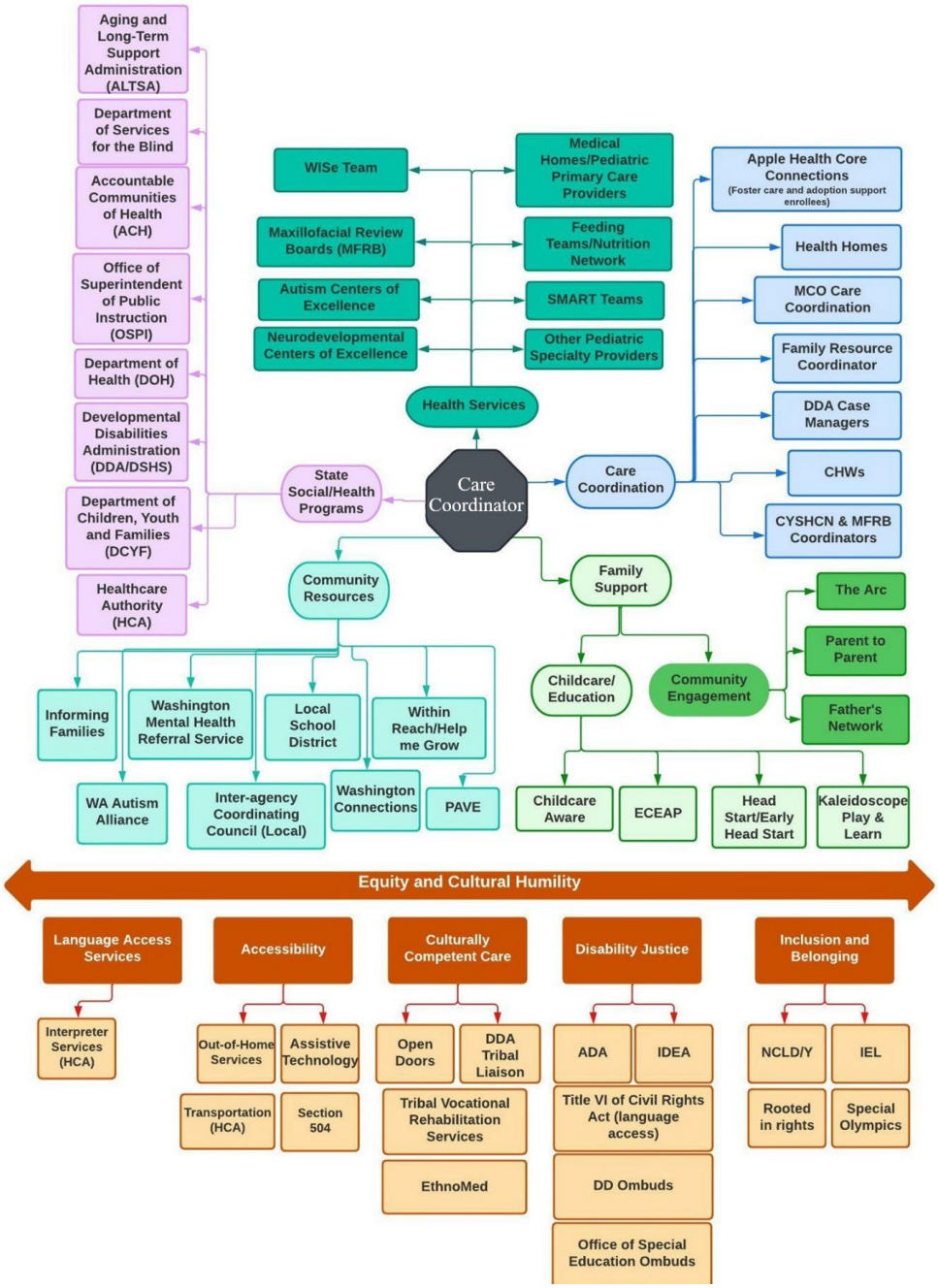


Figure 1. CYSHCN Systems of Care Map

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

CYSHCN Systems of Care: Terms Defined

Health Services

Medical Homes and Pediatric Primary Care Providers

Medical Home is a model of primary care that provides comprehensive, high quality, wrap around services; this model integrates family-centered care coordination and communication into CYSHCN's health system engagement[4, 16-23]. Medical homes are made up of a multidisciplinary team of primary care professionals, case managers, patient navigators, etc. This model reduces the burden of coordination and planning on families while simultaneously improving health outcomes for those involved. To get your client connected to a PCP who is participating in the Medical Home Model, you can utilize resources through the Washington State Medical Home Partnerships Project.

If your client is not connected to a medical home, their pediatric primary care provider is an essential connection, and should still be utilized as a central hub for navigating the client's primary medical needs and goals. You can provide technical assistance to local primary care providers to help increase their capacity to provide a medical home for their CYSHCN patients.

Feeding Teams/Nutrition Network

Because CYSHCN may be at an increased risk of nutrition-related challenges, connecting your client to a feeding team or a Registered Dietitian Nutritionist (RDN) who specializes in CYSHCN specific nutrition may be a helpful resource for your client. The Nutrition Network provides a variety of resources to find both feeding teams and specialized dietitians in your area. In addition, some Neurodevelopmental Centers of Excellence (NDCs) include RDNs and feeding teams within their center. Check with your local NDC to find out if that service is available locally and refer to the Nutrition Network website for resources and a list of providers.

Neurodevelopmental Centers of Excellence

Neurodevelopmental Centers of Excellence (NDCs) are non-profit and hospital-based agencies who provide therapy and related services to young children with neuromuscular or developmental disorders. There are 18 NDCs across Washington state, and they all serve a variety of age groups, with many focusing on the birth to 3 population. These clinics are an important referral resource for CYSHCN Care Coordinators as NDCs can reduce the burden of health system navigation for parents; they have a variety of therapy providers all in one place for families and they have FRCs on staff for families of children under 3. To get connected with a local NDC you can reference this map of all the NDCs and the contact information of each agency.

Autism Centers of Excellence

Autism Centers of Excellence (COE) are a crucial resource for children to obtain an autism diagnosis. A COE could be any medical practice, psychology practice, multidisciplinary assessment team, or individual provider who has either received COE training through the Healthcare Authority (HCA) or has been judged by the HCA to be qualified to diagnose autism and write a prescription for ABA services. Applied Behavior Analysis (ABA) therapy is a model of support and education for those who have been diagnosed with autism as an intervention for providing tools and support in navigating their environment. ABA therapy is only eligible as a covered service through Apple Health if a child

has been diagnosed with autism by a COE; therefore, knowing how to connect with your local COE is an important referral pathway to support your CYSHCN clients.

SMART Teams

School and Medical Autism Review Team (SMART) is a mechanism for families to navigate the long wait times in tertiary medical centers. SMART teams partner with COEs as a validated source to inform the autism evaluation and diagnosis using an interdisciplinary approach. These teams are a key resource in rural and underserved communities because they build and expand services via existing community resources. Pediatric primary care providers partner with schools, early intervention agencies, and families using the SMART model to inform autism diagnosis. This map of SMART networks is a great resource to find your local SMART team. You can also contact Kate Orville for additional questions and support.

Other Pediatric Specialty Providers

CYSHCN may have a variety of unique needs and may require support from a diverse pool of providers to gain the necessary therapeutic support. The following are a list of some important providers to keep in mind when considering the needs of your CYSHCN clients:

Speech Language Pathologist (SLP) - SLPs may support CYSHCN with any type of language, communication, feeding and swallowing challenges. SLPs can evaluate and treat a range of conditions. SLPs can exist in a community setting, schools, NDCs, and specialized medical clinics.

Occupational Therapist (OT) - OTs may support children who experience a health challenge such as a cognitive, physical, or sensory difference, that impairs their ability to function. OTs provide therapy to learn or re-learn how to perform tasks of daily life such as brushing teeth, self-feeding, and getting dressed by focusing on developing fine motor skills and improving hand-eye coordination.

Physical Therapist (PT) - PTs may support children by improving strength and supporting gross motor skill development such as walking, running, and playing.

Registered Dietitian Nutritionist (RDN) - RDNs may support children by performing nutritional assessments and providing guidance and resources for the unique nutritional needs of some CYSHCN.

WISe Team

Wraparound with Intensive Services (WISe) is a behavioral health service provided through the HCA and is voluntary for all Apple Health clients. WISe provides intensive mental health support to youth aged 20 or younger with behavioral health needs and who meet medical necessity criteria for WISe services. WISe is a unique model in that it uses a team approach and lets the children and families define their goals and success through strengths-based, individualized care plans.

Maxillofacial Review Boards (MFRBs)

Maxillofacial Review Boards (MFRBs) are located in each region in Washington and are multidisciplinary teams serving infants and children born with oral facial anomalies like cleft lip and

cleft palate. Each team has a nurse that serves as the team coordinator and supports families to schedule children for team review, facilitates visits as necessary, and summarizes information and recommendations prior to the MFRB team review. You can find your regional MFRB Coordinator on the CYSHCN MFRB webpage.

Care Coordination

Apple Health Core Connections

Core Connections is a statewide managed care health plan specifically supporting Apple Health Foster Care clients. Core Connections provides individualized care management services to support chronic condition care and education at no cost to their clients. If you have a CYSHCN in the foster care system who needs more intensive care coordination services than you can provide, connecting them with this resource can serve as a warm hand off for your client to receive the specialized support they need.

Fostering Well Being

Fostering Well Being provides care coordination for infants, children and youth in foster care who are eligible for Apple Health (fee-for-service Medicaid), who are also Tribal-affiliated or in tribal custody (and have not opted to enroll in managed care organization (MCO) due to being American Indian/Alaska Native), non-citizens or those existing enrolled clients (prior to April 1, 2016) in HCA's Medically Intensive Children's Program (MICP). Fostering Well Being is a program through the Department of Children, Youth, and Families (DCYF).

Health Homes

Health Homes is a program that provides case management services for clients in the setting requested by the CYSHCN and their family. If eligible and enrolled into this program, the services continue indefinitely and do not have an age limit or an opportunity to age out of the system. Eligibility is based on health system utilization, determined by a Predictive Risk Intelligence System (PRISM) score. Utilization scores may be low for very young children because they have not had as much time to engage in the health system, but if you think your client may benefit from the service and be on the cusp of eligibility, you can reach out to the program administrator to request enrollment at the following email address: healthhomes@hca.wa.gov . See the Health Home Fact Sheet in the Appendix for more information.

CYSHCN Coordinator

Each local health jurisdiction (LHJ) has a *CYSHCN Coordinator* on staff. The responsibilities of the CYSHCN Coordinator varies at each LHJ depending on the capacities of each agency. However, the roll all CYSHCN Coordinators play across the state is to serve as the support and advocate for CYSHCN and their families from birth to age 18[1]. CYSHCN Coordinators support this need by serving as an accessible point of contact, they also offer guidance, resources, and referrals.

[1] In some cases CYSHCN may receive support to age 21

CYSHCN Coordinators often wear many hats within the agencies they serve, and it is not feasible for CYSHCN Coordinators to provide direct care management and care coordination for all clients in all counties across the state. Providing direct care management may not be necessary and may be a duplication of efforts as there are various systems and services that exist to provide intensive client care and case management. One of the most essential services a CYSHCN Coordinator may offer is serving as a facilitator and support in warm hand offs and referrals depending on the identified needs from the family.

CYSHCN Coordinators are the only available resource to CYSHCN from birth to adulthood without additional enrollment or specific parameters and barriers to engagement. DOH hopes to leverage the ubiquitous nature of the work that CYSHCN Coordinators are already doing. We want to provide guidance and resources to help CYSHCN Coordinators connect their clients to existing supportive services in Washington.

MCO Care Coordination

Managed Care Organizations (MCOs) provide care coordination services as part of the benefits included in their plans. The degree of care coordination varies depending on the need of the client and can range from simple coordination of care and services to intensive case management. Informational slides are available on MCO Care Coordination services from the CYSHCN Program's July 2022 Communication Network Meeting (pg. 31-48). As indicated by the graphic below, there are overlapping activities between CYSHCN Coordinators and MCO Care Coordinators. Both:

- may connect their clients to needed resources,
- may partner with other pertinent systems of care, and
- may address health and safety needs.

Because of these overlapping duties, if a CYSHCN Coordinator deems it appropriate, they may request to partner and collaborate directly with the MCO Care Coordinator. This partnership may be requested by following the MCO referral and contact request protocols identified in this toolkit.

In general, a CYSHCN Coordinator's role is to ensure the client is connected to their MCO Care Coordinator if they need additional support. For guidance on how to refer and request Care Coordination and Case Management Services from MCOs, please see the MCO Referral Resource in the appendix. The MCO Referral Resource also contains the contact information for the MCO Points of Contact and the MCO CYSHCN Coordinators

The CYSHCN program encourages CYSHCN Coordinators to utilize these care coordination and case management resources with the intent of **reducing duplication of work and expanding CYSHCN Coordinator capacity** with the increased support. Please reach out to the CYSHCN program if you

encounter any barriers to engaging with theses existing resources; the program is available to offer guidance and resolution.

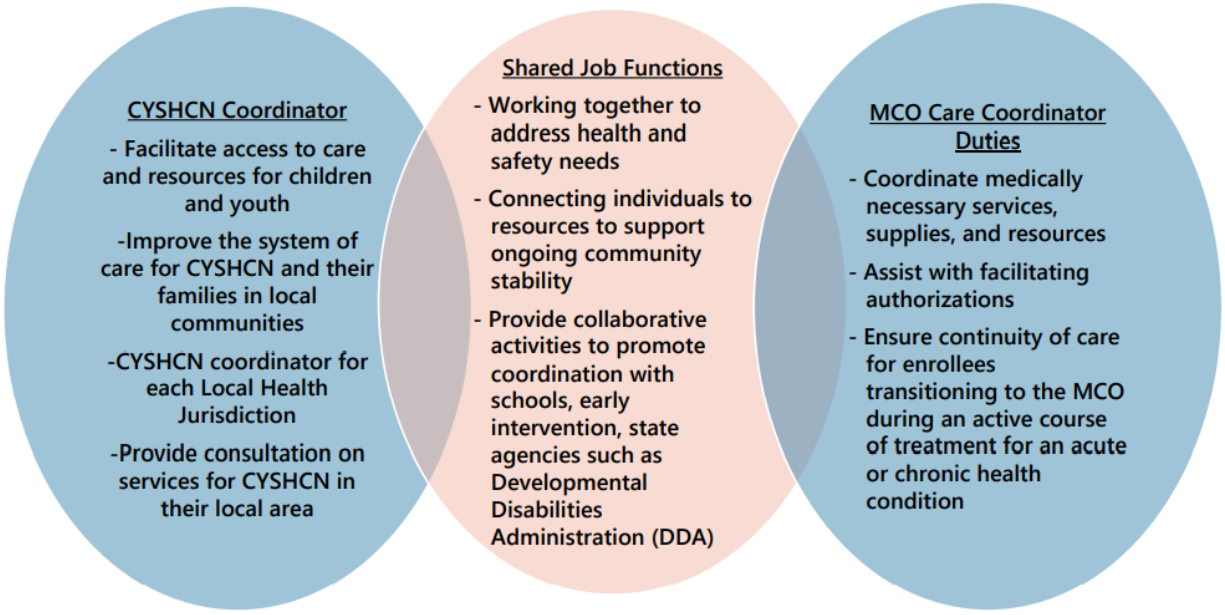


Figure 2. Created by Kathleen D. (HCA)

Family Resource Coordinator

For CYSHCN enrolled in Early Support for Infants and Toddlers (ESIT), a *Family Resource Coordinator (FRC)* is assigned to the family and made available for case management support. An ESIT FRC[2] can help with resource referrals, supporting the goals of the family, and ensuring warm hand offs and smooth transitions out of ESIT services when the child turns 4. In addition, FRCs ensure that families gain the necessary early intervention services they need while a child is enrolled in ESIT, as well as receiving the rights and procedural safeguards for the early intervention program. Prior to a child aging out of ESIT services, it is recommended that the FRC connect with the CYSHCN Coordinator to ensure a warm hand off and prevent gaps in care.

DDA Case Managers

A CYSHCN who is an **enrolled** client of the Developmental Disabilities Administration (DDA) and is receiving a paid service from DDA can gain support from a DDA *Case Resource Managers (CRM)*. CRMs help clients with access to relevant care resources and DDA services. If a CYSHCN you are working with is a DDA client receiving a paid DDA service and does not have a CRM, you can help them fill out a Service Referral and Information Request or call DDA to request one.

Community Health Workers

Community Health Workers (CHW) are individuals who live and work in their local community to provide education, access, and resource support for health and social needs. CHWs can meet clients

[2] ESIT Statewide directory (wa.gov)

in local community settings and can provide a variety of supports ranging from checking blood pressure to resource referral and advocacy. Care Coordinators can connect with a local CHW through DOH contacts, the Washington Community Health Worker Association, and through some Managed Care Organizations and community health centers.

Family Support

The Arc of Washington

The Arc of Washington State is a non-profit organization that provides various advocacy and community engagement programs and resources for individuals with intellectual and developmental disabilities (I/DD) and their families. Connecting CYSHCN and their families with this resource may be helpful for Parent to Parent and Parent Coalition connections, advocacy supports, family mentors, and other appropriate resources.

Parent to Parent

Parent to Parent (P2P) is a valuable community connection resource for CYSHCN families. P2Ps can provide a connection point to a community of parents and children with special health or developmental concerns. P2P can also offer emotional support and educational resources for families. Navigating chronic health conditions and developmental disabilities in the family can be isolating, emotional, and challenging. Access to support groups that include parents with lived experience and are trained in trauma informed care is an important resource for families. P2P also offers trainings for parents of CYSHCN who may be interested in becoming a Volunteer Helping Parent. You can connect CYSHCN families to Parent to Parent by reaching out to a P2P Coordinator.

Washington State Fathers Network

Washington State Fathers Network can provide community support for fathers and male-identifying caregivers of CYSHCN. The Fathers Network connects male-identifying caregivers with each other and offers support for fathers to share their stories by promoting inclusion. You can visit the Washington State Fathers Network website for more information, contacts for the 11 local chapters across Washington, and their regular meeting schedule.

Childcare and Early Child Education

Head Start

Head Start is a federally-funded program through the U.S. Department of Health and Human Services. This program promotes school readiness for children birth to 5 from low-income families. This free learning and development program also serves as free childcare for eligible children. Eligibility is based on if a family is at or below 130% the Federal Poverty Level[3]. Families receiving TANF, SSI, or SNAP and children in foster care or children experiencing housing insecurity are eligible regardless of income. Families can apply for Head Start through their Head Start Locator.

[3] You can find more information in the Poverty Guidelines Resource

Early Head Start

Early Head Start provides the same services as Head Start but serves infants and toddlers under the age of 3 and pregnant people. They provide comprehensive child development and family support for infants and toddlers from low-income families. Early Head Start also welcomes children with special health care needs. The eligibility and application process are the same as Head Start, see above.

Early Childhood Education and Assistance Program

Early Childhood Education and Assistance Program (ECEAP) is facilitated through the Washington State Department of Children, Youth and Families. ECEAP serves children 3 to 5 years old. The program provides free early learning, childcare, and preschool and has a focus on family involvement and support. ECEAP eligibility is based on if a family is at or below 36% of the state median income. Some children over the income limit may be accepted if there are developmental or environmental concerns. Some locations offer early ECEAPs, supporting infants or toddlers younger than 3 years old. Early ECEAP eligibility requires a family to have an income at or below 50% of the state median income.

Kaleidoscope Play and Learn

Kaleidoscope Play and Learn is a play group for young children and their caregivers to meet weekly in a facilitated play-based and educational environment. The facilitated play is based on best practices in developmental learning and growth. It is a Promising Practice by the University of Washington's Evidence Based Practice Institute and is a free service for families available to young children on a drop-in basis. Meetings happen in convenient community locations where families already live such as libraries, schools, and community centers, some locations also have multilingual groups available to join.

Childcare Aware of Washington

Childcare Aware of Washington is a nonprofit organization that facilitates access to high-quality childcare and early learning programs. Childcare Aware supports both resource and referral to childcare for families and education and guidance for statewide providers. Parents can find a local provider by using their customizable search domain.

Community Resources

County Interagency Coordinating Councils

County Interagency Coordinating Councils are hosted and coordinated through the Washington State Department of Children, Youth and Families (DCYF). They provide easy access to early intervention services and build community capacity. The councils have a multidisciplinary team which includes providers, community partners, and families with children ages birth to 12 who identify as having a disability and/or developmental delay. DCYF also hosts different community engagement groups including a Parent Advisory Group. You can connect CYSHCN families and caregivers to these resources if they're interested in community advocacy and program development.

Local School Districts

Local School Districts are a vital resource connection for CYSHCN and their families. Schools are required by the Individuals with Disabilities Education Act (IDEA) and WAC 392-172A to provide students with disabilities a free and appropriate public education (FAPE). They can help make sure CYSHCN have the essential resources, accommodations, and support they each need. School is an important connection point for assessments and referrals to multiple resources relating to health, education, and social determinants of health. Some CYSHCN may receive therapies through in-school providers. Here are a few examples:

- If you need to connect with a local school nurse or health supportive resource, reaching out to the Office of the Superintendent of Public Instruction's Health Services contact can be an important referral point.
- If you receive a client who needs additional supportive medical care while in school and doesn't have a school nurse connection, start by reaching out to the health services contact.
- If your CYSHCN client needs evaluation and assessment in school, make sure that parents are aware they are entitled to an evaluation.
- Offer families guidance and advocacy on accessing information and resources on FAPE.
- Use the PAVE Behavioral Health Toolkit to find additional information and guidance.
- Anyone can refer a student for an evaluation if there is a concern or challenge in school such as academic, social, behavioral, etc. Child Find is the process that coordinates and identifies children who may need evaluation for special education and related supportive services.
- Families facing a variety of social determinants of health such as food and housing insecurity can reach out to their school to connect with resources to support their child's full participation and attendance at their local school.

Help me Grow and AS360

Help me Grow and AS360 are a collection of Washington state specific search engines for CYSHCN resources. They intersect in multiple ways and may offer overlapping resources, but they are an important part of providing support to CYSHCN and their families. You can help your clients know about these sites and make sure families know how to navigate them. If a family doesn't have technology resources to use these tools, they may benefit from using meeting time to navigate these resource engines and help address a family's social and political determinants of health.

PAVE

PAVE is a consolidated resource tool and an educational and community support resource for Washington State CYSHCN needs. PAVE provides a variety of educational trainings, toolkits, and handouts for CYSHCN and their families. They cover everything from early learning and school-age education needs, parent and family supports, health and wellness, and more.

PAVE has several programs that specialize on resources and information for CYSHCN families:

- Parent Training and Information (PTI) offers families and providers information about early and K-12 education and related services for CYSHCN ages 0-26.
- Family to Family Health Information Center (F2F) supports families and providers through resources, advice, and assistance finding funding for necessary healthcare services. F2F

supports two staff who offer care coordination services to families in the rural peninsula region. F2F also hosts a new Type 1 Diabetes Statewide Coordinator who can work with families to facilitate access to resources, training and education, and peer-to-peer supports.

- Parent to Parent for Pierce County is hosted through PAVE. See Parent to Parent for more information.
- Specialized Training of Military Parents (STOMP) supports military families who have a child who has special health care or educational needs. STOMP serves military families across the country and those stationed overseas.
- Lifespan Respite WA offers information on respite sources and services, including programs that pay for respite care.
- StartNow! supports students with disabilities who are in middle and high school to take an active role in their transition to adulthood through interactive opportunities.

Informing Families

Informing Families is an educational hub that offers information about stages of life for CYSHCN through their life. It also provides information about CYSHCN eligibility, applications for systems of care, news, advocacy, and other resource information. Their educational videos for different CYSHCN age groups are helpful for providers and families.

Washington Mental Health Referral Service

Washington Mental Health Referral Service is a free telephone-based referral service funded by the Healthcare Authority and facilitated by Seattle Children's Hospital. This referral service provides CYSHCN with outpatient mental health services in their local community. Families can access this service using an online request form or by calling 833-303-5437. This service also faxes relevant information to the CYSHCN's provider to improve continuity of care and communication if the family consents.

In addition, the Washington Partnership Access Line (PAL) is a resource specifically for primary care providers to utilize when they have questions about mental health care including diagnosis, medication adjustment, and treatment planning. CYSHCN Care Coordinators may access PAL's website for additional resources and Care Guides.

Washington Connections

Washington Connections is an application platform for Washington residents to determine their eligibility for and connection to supportive services. Services available on this platform include housing assistance, EBT, Long Term Care support, Legal Support, Transportation Assistance, and more. Please note this is an essential resource to connect families to, particularly if you've identified any social or political determinants of health.

WA Autism Alliance

Washington Autism Alliance provides individual and statewide advocacy for individuals with Autism Spectrum Disorder (ASD), developmental disabilities, and resources to support the needs of children and families. They also offer a parent support group and mental health counseling for parents.

Type 1 Diabetes Workgroup

The DOH CYSHCN team facilitates a monthly workgroup of health care providers, community partners, and families dealing with Type 1 Diabetes (T1D). The workgroup has created resources and projects based on provider survey feedback and a family-focused listening session. They are also building social connections with the Washington and Montana Teen Connect virtual platform to help support teens with T1D. This workgroup has supported a T1D Statewide Coordinator position to create a Helping Parent training and matching program for families with T1D teens —similar to Parent to Parent's Helping Parent model.

Washington State Hands & Voices

Hands & Voices provides unbiased support to families with children who are Deaf or Hard of Hearing through their program, The Guide By Your Side (GBYS). This peer-support program matches trained and experienced parents of children who are Deaf or Hard of Hearing with families who have recently learned of their child's hearing condition or who have older children navigating the challenges of transitioning to adulthood. GBYS programs also include an option for Deaf or Hard of Hearing Guides (DHH Guides) who are Deaf or Hard of Hearing adults and specially trained to support families.

Washington Sensory Disabilities Services

Washington Sensory Disabilities Services supports the developmental and learning needs of children aged birth to 21 who are Deaf or Hard of Hearing, Blind or low vision, and DeafBlind. They provide resources and support to birth-to-three professionals, teachers, SLPs, educational interpreters, and families.

Social/Health System Services

Aging and Long-Term Support Administration (ALTSA)

Aging and Long-Term Support Administration (ALTSA) is located within the Department of Social and Health Services (DSHS). ALTSA supports seniors and people with disabilities to access the services and resources necessary to attain good health, independence, dignity, and control over decisions that affect their lives. ALTSA coordinates and facilitates a variety of services and programs such as Home and Community Services, Residential Care Services, and Adult Protective Services. These resources can be particularly helpful for CYSHCN transitioning into adulthood.

In addition, ALTSA houses two pertinent CYSHCN services: Fostering Well Being and the Office of Deaf and Hard of Hearing.

Fostering Well Being (FWB)

Fostering Well Being (FWB) is a program that is housed under DSHS/ALTSA. FWB ensures appropriate care coordination of health/behavior and mental health care services for the following populations:

- Tribal-affiliated or in tribal custody who have not opted into managed care
- Non-citizen
- Existing enrolled clients (prior to April 2016) in HCA Medically Intensive Children's Program (MICP)

The FWB program can support the previously identified fee-for-service CYSHCN with health focused care coordination, consultation, medically fragile group home oversight, and partnerships with multiple pertinent CYSHCN partners, agencies, and Managed Care Organizations. CYSHCN Care Coordinators can make referrals to FWB by completing their Referral Form and emailing it to fwb@dshs.wa.gov (preferred). The same email can also be used for general questions as well as the following phone number: 1-800-422-3263 ext. 52626/option 5.

Office of Deaf and Hard of Hearing

Office of Deaf and Hard of Hearing (ODHH) is housed withing the DSHS/ALTSA and provides a variety of supportive services for those that are Deaf, Deafblind, Deaf Disabled, Hard of Hearing, Late Deafened and Speech Disabled, their families, and their service providers. ODHH can support CYSHCN with access to technologies, consultations, information, referrals, and resources. In particular, ODHH is a helpful resource and advocate for accessible telecommunication equipment, family mentor programs for those that are Deaf and Hard of Hearing, Reasonable Accommodation support, and Sign Langue Interpreter access and guidance.

Department of Health Relevant Programs

Washington State Department of Health (DOH) hosts, funds, and facilitates different Public Health interventions, including Women, Infants, and Children (WIC), provider credentialing, and much more!

Children and Youth with Special Health Care Needs

The Children and Youth with Special Healthcare Needs (CYSHCN) program is supported by state funds and several grants, including the Maternal and Child Health Block Grant.

The CYSHCN program promotes an integrated system of services for CYSHCN across Washington. Our services help CYSHCN and their families participate, belong, and thrive in their communities. We support their physical, mental, developmental, social, educational, and emotional well-being through integrated, accessible systems of care.

CYSHCN Care Coordinators can contact the CYSHCN program for resources and specialized support on topics like Family Engagement, Nutrition, Mental and Behavioral Health, and direct consultation. You can also access and distribute our CYSHCN Brochures for Families (available in 16 languages) to the families you work with.

Early Hearing Detection, Diagnosis and Intervention

The Early Hearing Detection, Diagnosis, and Intervention (EHDDI) program helps infants born in Washington receive a newborn hearing screening at birth. This program also works to ensure that infants identified as Deaf or Hard of Hearing are referred for early support services as soon as possible. The EHDDI program webpage has educational materials for families and providers. The Resource Notebook for Families of Children Who are Deaf or Hard of Hearing, available online in six languages, is a great resource for families with children who are Deaf or Hard of Hearing. Family Resource Coordinators and early support providers can access online training modules about working with children who are Deaf and Hard of Hearing and their families.

Childhood Lead Poisoning Prevention Program (CLPPP)

The Childhood Lead Poisoning Prevention Program (CLPPP) is housed in the DOH division of Environmental Public Health. Even low levels of exposure to lead can harm developing brains and bodies. Children who are exposed to lead may have symptoms such as hearing problems, growth delays, and increased behavior and attention-related challenges. One reason testing for lead exposure is recommended is if children are experiencing development challenges, even if there are no physical symptoms present. The CLPPP offers guidance and resources to those working with families who may be affected by lead exposure. Check the website for publications and resources and reach out to lead@doh.wa.gov with any questions.

Other Related Programs at the Department of Health

- The Newborn Screening program coordinates evaluations, assessments, and payments for newborn screenings, like the initial hearing screening and the blood spots that test a variety of rare congenital conditions. The Parent Resource Page offers multilingual education and resources for newborn screenings.
- Universal Developmental Screening (UDS) helps support childhood development through regular screenings to help identify developmental delays. UDS also offers parents, providers, and early learning partners access to the Strong Start data screening system. Strong Start is a free online system to help track and save completed developmental screening records for CYSHCN from birth to 5.

Developmental Disabilities Administration

Developmental Disabilities Administration (DDA) is a Washington State system of care within Department of Social and Health Services (DSHS). DDA provides support and fosters partnerships to empower people with intellectual and developmental disabilities and their families to live the lives they want. DDA clients can access a variety of educational and supportive services. If your CYSHCN client may be eligible, they must review the eligibility requirements and apply to become a DDA client. Even if a client's DDA application is rejected, it does not mean they are ineligible. An application can be rejected because of missing information or errors in the original application. Clients can make the needed corrections and apply again. Community programs such as PAVE and Informing Families can help with DDA applications. DDA provides a variety of program and service factsheets on their website.

The Washington State Department of Children Youth and Families

The Department of Children, Youth, and Families (DCYF) hosts a variety of programs to support families. Their programs include adoption, foster caregiving, child protective services, and the Early Support for Infants and Toddlers (ESIT) program. ESIT is an early intervention service for CYSHCN aged birth to 3 with developmental delays or disabilities. It offers wrap-around support in home and community settings and provides therapy, education, and resources for CYSHCN and their families. Therapies available to ESIT CYSHCN include specialized instruction, speech therapy, occupational therapy, and physical therapy. Family Resource Coordinators (FRCs) are assigned to ESIT participants and help make sure that CYSHCN families receive the needed care throughout the process. FRCs also support a warm hand off when CYSHCN age out of this program. Refer to the ESIT Referral Contacts by County and School District to find an ESIT program to facilitate warm hand offs.

Health Care Authority

Health Care Authority (HCA) coordinates and distributes health care insurance and services for more than 1 in 3 Washingtonians. HCA coordinates Medicaid, Medicare, and some types of private insurance. HCA is an important touch point for CYSHCN to connect to Apple Health and its many associated supportive services and branches. Apple Health coordinates with the 5 Managed Care Organizations (MCOs) in Washington to help distribute insurance to clients. You can support your client's access to health insurance by ensuring they have applied for Apple Health if they're eligible. You can also coordinate and collaborate with their assigned MCO CYSHCN Coordinator and/or care manager.

Department of Services for the Blind

Department of Services for the Blind provides resources, support, and coordination for individuals of all ages with different visual capacities, including those who may have low vision and are blind. DSB offers employment access and retention resources, adaptive and supportive equipment, youth services, vocational rehabilitation, and business engagement. You can support your client by requesting services through the DSB self-referral form.

Accountable Communities of Health

Accountable Communities of Health (ACH) are independent organizations located in 9 regions across Washington. ACHs are funded through the HCA and work to support the needs of their communities by supporting specific health care and social needs projects. You can identify your regional ACH through their webpage. You can also identify existing local projects that may support your CYSHCN clients' social and political determinants of health.

Office of Superintendent of Public Instruction

Office of Superintendent of Public Instruction (OSPI) oversees public education and related services, including Special Education. OSPI collaborates and guides 295 public school districts and 6 state-tribal education schools. Special Education provides adaptive, supportive, high-quality, and comprehensive education to students who would benefit from such care.

You can send referrals to the special education support team to help your clients access needed educational supports. You may also receive a referral from your local school district to ensure that the CYSHCN has wrap-around services from various support mechanisms. It's important to have contact with your local school districts for appropriate referrals and coordination between systems of care.

Equity and Cultural Humility

Language Access

Interpreter Services

Interpreter Services are an important resource and admittedly a challenging one to access at times. HCA offers interpreter services for their Apple Health clients as well as to school and public employees. In medical settings providers are required to have spoken and sign language access according to the Title VI of the Civil Rights Act and the Americans with Disabilities Act. CYSHCN Care Coordinators can support their clients by advising CYSHCN and their families to request interpreter services when they make their medical appointments to ensure their rights and needs to understand their medical care through the appropriate language are met. Sign Language Interpreter services are also available through the Office of Deaf and Hard of Hearing (OFHH). To access sign language interpreters, see the Registration page at ODHH as well as the Interpreting Services FAQ on the ODHH page. HealthPoint has a search portal that allows users to search for providers based on location and language spoken by the provider.

Accessibility

Foster Care

Foster Care, sometimes referred to as Out of Home Care, is coordinated through DCYF. If your CYSHCN client needs foster care supports or advocacy, reaching out to DCYF is an important place to start. DCYF also coordinates safety and wellbeing of CYSHCN; if a CYSHCN Care Coordinator has any concerns about neglect and unmet needs, reaching out to DCYF can provide direction and resources for resolution.

Assistive Technology

Assistive technology is the term used by DSHS to describe equipment, devices or systems available to help support independence. Assistive technology is available for individuals with intellectual and developmental disabilities who are enrolled in the following DDA services: Individual and Family Services Waiver (IFS), Children's Intensive In-home Behavior Supports (CIIBS) waiver, Community First Choice (CFC), Pre-Admission Screening and Resident Review (PASRR), and Roads to Community Living (RCL). CYSHCN Care Coordinators can encourage their CYSHCN clients to connect with their DDA case manager for assistive technology access. In addition, the Washington Assistive Technology Act Program (WATAP) is another program to consider as they provide resources, services, and training for persons with disabilities and seniors in the use of assistive technology.

Section 504 of the Rehabilitation Act

Section 504 of the Rehabilitation Act is a national law that protects a student's right to accommodations, modifications, non-discriminatory support, and anti-bullying in their educational setting. Accommodations include a student's choice of seating, specific restroom pass or access, not calling on students to respond orally during group instruction, and positive behavioral supports and Behavioral Intervention Plans (BIP). PAVE has resources for educational supports.

Transportation Services

Washington state has a variety of transportation resources that may be supportive to the needs of your CYSHCN client.

HCA provides accessible non-emergency transportation services via public bus, taxi, wheelchair van, airplane, and ferry tickets. CYSHCN parents may find **gas vouchers** and **reimbursement for vehicle mileage** particularly helpful. Eligibility for transportation services are as follows:

- A current ProviderOne services card,
- No other way to reach the healthcare appointment, and
- The appointment must be covered by the Apple Health Program.

CYSHCN Care Coordinators and families may access this service by reaching out to the HCA transportation broker in their county; the broker will provide resources and guidance on accessing the transportation support needed.

Some CYSHCN will qualify for a disabled parking placard. The Department of Licensing provides resources and guidance on eligibility and how to get or renew a disabled parking placard. There is an application form that CYSHCN Care Coordinators may help families complete and submit.

The Washington Department of Transportation offers discounted fares for those who have a qualifying disability, including reduced ferry tickets.

Some counties offer reduced fare permit for those with a qualifying disability, including the King County Metro, Yakima, Spokane, and other counties.

Culturally Competent Care

Open Doors

Open Doors for Multicultural Families provides culturally and linguistically relevant services and education to diverse families of persons with developmental and intellectual disabilities across the life course. They offer a variety of programs, resources, and events, serving immigrant and refugee families and families of color. Open Doors is located in and primarily serves the King County area. Open Doors uses a cultural brokerage model to navigate the systems of care for their clients and families. You can connect your CYSHCN clients and families who need culturally competent care and services by linking them to Open Doors.

Developmental Disabilities Administration (DDA) Tribal Liaison

A DDA Tribal Liaison supports policies and laws that respect tribal sovereignty, negotiates agreements, provides technical assistance and training to staff and tribes, and promotes DDA services and supports. You can connect your CYSHCN clients to their tribal liaison for support accessing tribal services.

Tribal Vocational Services

Tribal Vocational Services is offered by the Department of Services for the Blind. This service provides support for American Indians with disabilities looking for employment opportunities. It helps that clients receive the full vocational rehabilitation services possible. PAVE offers an educational page regarding Tribal Vocational Rehabilitation Services.

EthnoMed

EthnoMed provides convenient social and cultural details relevant to clinical care. They offer resources and information on cultural beliefs, medical issues, and other topics related to the health care of immigrants in the US. EthnoMed was developed for providers who support immigrant and refugee populations in the greater Seattle area, but has resources for families and providers alike that are relevant regardless of what part of Washington a CYSHCN resides in. CYSHCN Care Coordinators may utilize this resource if they are looking for resources for both patients and providers regarding immigration. They can also search clinical topics for culturally specific information or search culture, for insight on how to offer culturally competent care for that culture.

Disability Justice

Americans with Disabilities Act

Americans with Disabilities Act (ADA) prohibits the discrimination of individuals with disabilities in employment, transportation, communications, access to state and local programs, and more. Familiarity with ADA is crucial so that CYSHCN and their families are not discriminated against or denied access to resources that are their right.

Individuals with Disabilities Education Act

Individuals with Disability Education Act (IDEA) protects special education rights; and has four primary principals:

- The right for a student to have a **Free Appropriate Public Education (FAPE).**
- The right to an appropriate **Evaluation** (it requires schools to provide evaluations for students who may need additional support due to a disability).
    - Child Find Mandate is the resource to coordinate evaluations.
- The right to an **Individualized Education (IEP) Program**, which is a customized plan that allows students the extra help they need from teachers, specific instruction in social and emotional skills and general life skills.

- The right to the **least restrictive environment (LRE)** which encourages integrated classrooms of all students regardless of their disability status.

If disability may be a factor in school challenges, not limited to academic, social, and behavioral challenges, CYSHCN Care Coordinators can support their clients by ensuring they receive the necessary evaluation and accommodations they are entitled to through IDEA.

Title VI of the Civil Rights Act

Title VI of the Civil Rights Act prohibits discrimination on the basis of race, color, or national origin in any program or activity that receives Federal funds or other Federal financial assistance, including **language access**. CYSHCN and their families have a right to effective, equitable, and understandable care, communication, and health literacy information in their preferred language. Language access services must be offered at no cost to the family. They must be coordinated in a timely manner to allow CYSHCN families to access their health care and services. You can use this information to better educate, advocate, and inform families and caregivers of their rights.

Developmental Disabilities Ombuds

The Office of the Developmental Disabilities Ombuds seeks to inform the legislature's work by ensuring access to safe and high-quality developmental disabilities services. They collect, investigate, review, and resolve complaints made on behalf of those with developmental disabilities who are receiving state services. Examples of CYSHCN specific complaints may relate to abuse, neglect, exploitation, or **quality of or access to services**; their resolution process seeks to provide protection of choice and autonomy for CYSHCN. They are **not** affiliated with the Developmental Disabilities Administration (DDA) and may be able to help with any DDA related complaints. CYSHCN Care Coordinators may support CYSHCN and their families by connecting them to a DD Ombuds **when they have a complaint against a government agency or administration** or if they would like advocacy resource support.

Education Ombuds

The Office of Education Ombuds (OEO) in an independent Office that addresses questions about the K-12 public education system, supports collaborative problem-solving and conflict resolution within parent and school disputes, provides coaching, facilitation, training, and community engagement, and collects data and identifies trends to guide education policy recommendations. All the services provided by OEO are free, confidential, and collaborative. CYSHCN Care Coordinators can support their CYSHCN clients and families by connecting them to the Office of Education Ombuds when they have a question or unresolved problem with a school that is **affecting their student's education**.

10 Principals of Disability Justice

The 10 Principals of Disability Justice are important foundations for CYSHCN Care Coordinators, CYSHCN, and their support systems to be familiar with. The 10 principals were developed by Sins Invalid, a disability justice-based performance project that celebrates artists with disabilities, with an effort to centralize artists who are disabled and people of color, LGBTQ/gender-variant, and

communities who have been historically marginalized. The ten principals of disability justice are as follows:

1. Intersectionality
2. Leadership of those most impacted
3. Anti-Capitalism
4. Cross-Movement Solidarity
5. Wholeness
6. Sustainability
7. Cross-Disability Solidarity
8. Interdependence
9. Collective Access
10. Collective Liberation

CYSHCN Care Coordinators can incorporate these principals into their work with CYSHCN by understanding the intersectional nature of their clients and how that impacts the dynamic nature of their systems of support as well as their resource needs. Care Coordinators can support their CYSHCN clients with these principals and using language and framing that come from the perspective that CYSHCN and their families are whole and without deficit as they are.

Inclusion and Belonging

National Center for Learning Disabilities

The National Center for Learning Disabilities (NCLD) advocates for strong federal policies that impact those with learning disabilities, convene experts to discuss pressing issues in the field of learning disabilities, and publishes research and resources to improve practices in schools. Their mission is to reduce stigma, empower students, parents and educators, and mobilize advocates to create change. NCLD has a variety of helpful resources for CYSHCN and their families, including an Individualized Education Program (IEP) guide for parents, a transition guide written for students and young adults transiting out of high school, opportunities for CYSHCN leadership engagement and empowerment, and research and reports.

Institute for Educational Leadership

The Institute for Educational Leadership (IEL) works to build effective systems that prepare children and youth for postsecondary education, careers, and citizenship. They work to ensure that resources effectively provide equal opportunities for all children and youth to learn, develop, and become active participants in their communities. IEL prioritizes inclusive decision-making to ensure that all voices, particularly marginalized groups, are elevated. IEL has a variety of supportive resources for CYSHCN and their families including their resource and report page for Disability and Inclusion in children and youth.

Rooted in Rights

Rooted in Rights uses person-centered storytelling to produce media that amplifies perspectives from the disability community. They partner with Disability Rights Washington and community-led organizations to produce accessible advocacy content on disability rights issues. CYSHCN Care

Coordinators may find them a helpful partner for their county if there are disability rights issues that Care Coordinators would like help with sharing to the public. They also have a blog and video series that CYSHCN and their families may find informative and inclusive.

Special Olympics

Special Olympics (SO) is a space for CYSHCN and adults to play, feel included, and find community. Participants in the Special Olympics have the opportunity to discover new strengths, abilities, skills, and empowerment. SO also seeks to promote athlete leadership through their Athlete Leadership program; participants can develop leadership skills, undertake meaningful leadership roles, influence change in the SO movement, and create inclusive communities. This is a helpful resource for CYSHCN Care Coordinators to connect their CYSHCN client with if they are looking for opportunities to engage in community and incorporate healthy movement into their routine. CYSHCN with intellectual and developmental disabilities are eligible to participate in the young athletes program if they are between the ages of **2-7,** and the general program if they are **8 years or older**. CYSHCN will need to complete an Athlete Registration Packet and can get additional support by contacting their Athlete Support Hotline at (206) 231-6034 or by email.

Resource Referral Guide-Shared Plan of Care

As previously discussed, using a Shared Plan of Care is a recommended intervention in CYSHCN Care Coordination literature and DOH's CYSHCN Program. This tool intends to empower and support CYSHCN and their support systems by helping them map out their goals and to identify **what they consider success**. You can use the SPoC collectively to provide clarity and specificity towards reaching the desired goals and successes identified by CYSHCN.

The SPoC often contains:

- the child's goals and plans to achieve them
- the child's medical conditions
- what to do if a crisis occurs
- information about the child's support system/caregivers and important people in their life.

Using the SPoC, you can navigate the referral map below to better align your steps with CYSHCN and their family's goals.

In Washington state, CYSHCN family groups and relevant partners collaborated to identify and design a helpful navigation tool to meet their needs. CYSHCN families with lived experience helped identify and create this Roadmap tool, also available in Spanish. You can use this tool as a framework for the various political and social determinants of health where CYSHCN and the support systems may need resources and services.

Figure 3 is a non-exhaustive model highlighting different health determinants where CYSHCN may need support. You can use this figure with families and offer helpful prompts and examples. You can also use it to reference when working with CYSHCN clients from a holistic perspective.

The framework and theory of change in Figure 3 put the family at the center of the planning process. You can use motivational interviewing principles to help the family identify their success goals in fostering care and well-being for their CYSHCN. The SPoC can facilitate family sharing and

identification of resources and support. And finally, as you continue to engage with your clients, you can do so in an equitable, culturally competent, trauma informed, strengths based, and accessible way. For specifics about how to engage with CYSHCN clients respectfully, please reference the Inclusive and Trauma Informed Care Section of this Toolkit.

Find relevant links and resources for the various SPoC determinants in this toolkit's Shared Plan of Care Resource section.

Shared Plan of Care Map

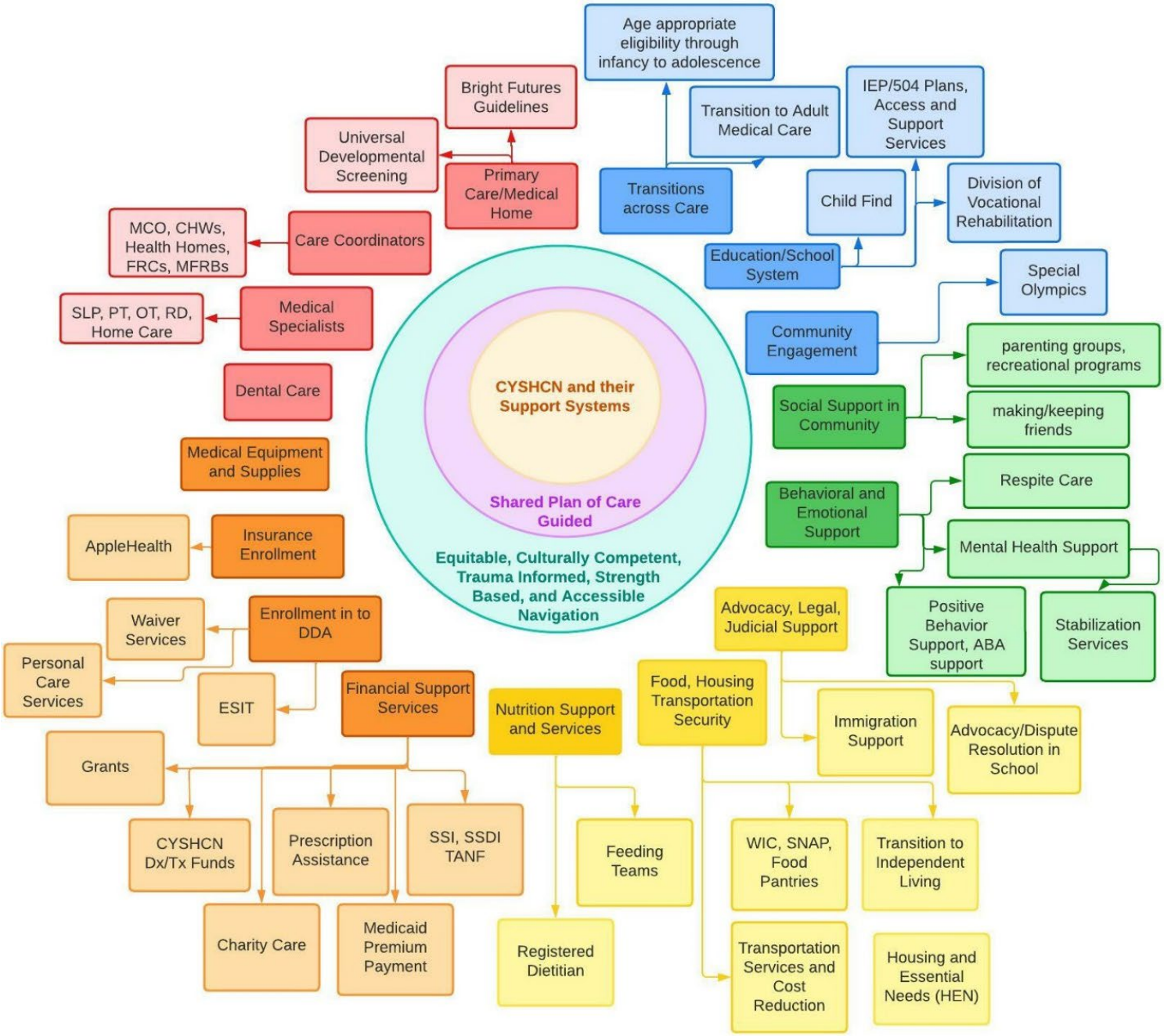


Figure 3. CYSHCN Shared Plan of Care Map

Shared Plan of Care Map Resources

AREAS OF SUPPORT	RESOURCES	NOTES
PRIMARY CARE/MEDICAL HOME	Bright Futures Guidelines SMART Teams Autism Center of Excellence In your County HealthPoint	**HealthPoint** allows users to search for providers and specialists based on the language access needs
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	
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 ESIT Services	
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. **NeedyMeds** has a comprehensive list of grants by diagnosis and state in addition to prescription assistance
NUTRITION SUPPORT	CYSHCN Nutrition Network Feeding Teams Type 1 Diabetes Statewide Coordinator Empowering Culinary Exploration: Tips for Teaching Cooking Skills to Youth with Disabilities	

	Understanding Eating Disorders in Adolescents – A Guide for Health Care Providers	
FOOD, HOUSING, TRANSPORTATION SECURITY	WIC Nutrition SNAP-Washington Connection Food Banks Housing and Essential Needs (HEN)-WA Connect Independent Living Roads to Community Living Independent Living Skills Program Non-Emergency Transportation	
ADVOCACY, LEGAL, JUDICIAL SUPPORT	Immigration Support-EthnoMed Developmental Disabilities Ombuds Education Ombuds Crystal Judson Family Justice Center Northwest Justice Project	
BEHAVIORAL AND EMOTIONAL SUPPORT (CHILD AND FAMILY)	Washington Mental Health Referral Service A Common Voice Service Animals Mental Health Assessment for Children National Maternal Mental Health Hotline _ MCHB.pdf NAMI Kinship Care Washington Partnership Access Line (PAL) WISe	When accessing **A Common Voice**, email Jasmine directly to set up a referral for family support groups for parents of CYSHCN: Jasmine@acommonvoice.org
SOCIAL SUPPORT	Washington Autism Alliance-Support Groups Peace Northwest National Parks Pass (FREE) WA Discover Pass (discounted) Special Olympics	
EDUCATION/SCHOOL	IEP/504 ADA Migrant and Multilingual Education GED/Tutoring (Learning Assistance Program) Home and Hospital Instruction after school programs medical absences Local School Districts	See Local School Districts description of Systems of Care Section
TRANSITIONS ACROSS CARE	School to Adulthood Transition Planning Transition Triangle Healthcare Transition Age Transitions-Informing Families	

CYSHCN Life Course Transitions and Eligibilities

CYSHCN comes in and out of contact with many systems of care at different times in their lives. In Washington State there are a variety of important enrollment windows and age specific services available to CYSHCN. But identifying and keeping track of the correct time to connect a CYSHCN client to age specific services can be challenging.

Figure 4 is a reference guide to help track CYSHCN's current stage in their age group. You can also see the upcoming services and resources available in the near future across various systems of care. This transition guide can ensure enrollment and connection to services in the present and plan and prepare applications for future service eligibility.

There are several urgent points of transition and enrollment that the CYSHCN program strongly encourages that you should know and support families through. We've identified these urgent transition points on the Life Course Transition Map with a star for quick reference. Urgent transition periods are:

- Applying for DDA at 4 and 19 years old.
- Applying for SSI at 18 years old.
- Ensuring a smooth transition from ESIT services to Special education services (3-4 years old).

These are also points where CYSHCN may not receive the "warm hand off" to continue their necessary care. We strongly encourage you to prioritize the above age transition periods and areas of focus, support, and education for CYSHCN and their families.

You can find the resources and direction associated with all the transition periods and services referenced in this toolkit's Life Course Transition Resource section.

CYSHCN Life Course Transitions Map

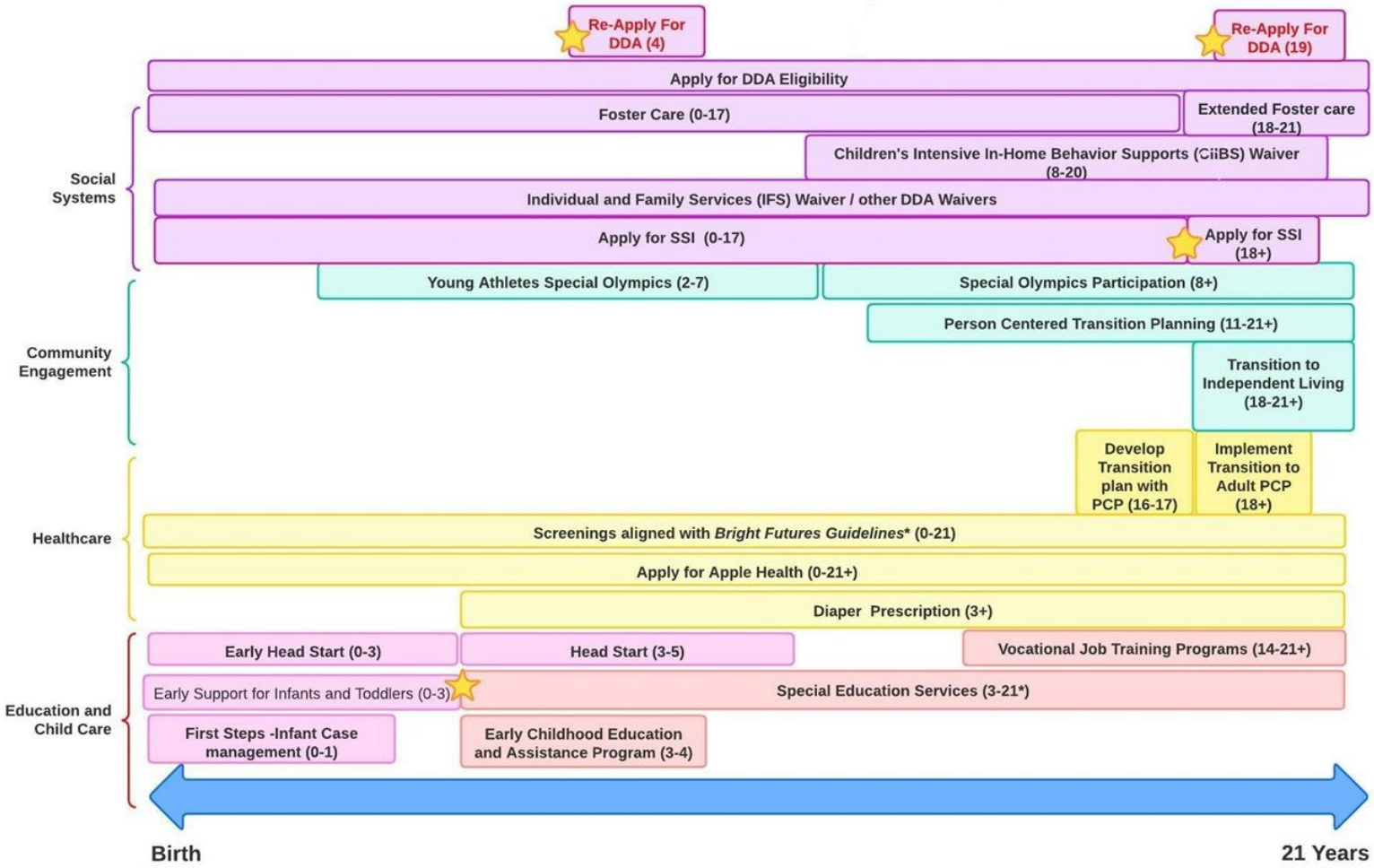


Figure 4. CYSHCN Life Course Transitions Map

CYSHCN Life Course Transition Resources

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 DDA Eligibility Video (PAVE)	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. 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. **Note**: DDA will send out a reminder letter to parents six months prior to the upcoming age for losing service, as a reminder to reapply. It is important to make parents aware of this reminder letter. 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. DDA Waivers provide access to Medicaid which can be very helpful for families with private insurance who experience financial barriers.
APPLY FOR SOCIAL SECURITY INCOME (SSI) 	SSI Fact Sheet Child Disability Report for SSI Social Security Help	### How Do I Apply for SSI for My Client? For your client to receive SSI, they will have to fill out **two forms and submit them to the Social Security Administration (SSA)**. The first is an **application for SSI**. They must contact the SSA either by phone or in person at a local office to set up an appointment to complete this application.

		The other required form is a **Child Disability Report**. You can access this form on the SSA's website and submit it online. **IMPORTANT:** CYSHCN should apply for SSI as soon possible regardless of their age. If CYSHCN are receiving SSI and are under age 18, they may need to reapply when they turn 18.
SPECIAL OLYMPICS	Special Olympics in Washington Young Athletes Special Olympics	See Special Olympics section Young Olympics for those **2-7 years** Special Olympics available for those **8 years and older**
PERSON CENTERED PLANNING	Open Doors-Transition guide Life course Nexus Person Centered Planning (Informing Families) Person Centered Planning-PAVE	Begin person centered planning at **age 11** to begin goal setting and strengths-based development towards your clients determination of their own personal success (education, work, recreation).
TRANSITION TO INDEPENDENT LIVING	Washington State Independent Living Council Roads to Community Living Wise Center for Change in transition Services (CCTS)	Available for though **18-21+**
MEDICAL TRANSITION PLANNING	Slide Deck on Youth with Special Needs and Transition from Pediatric to Adult Care Pediatric to Adult Transition Resource and Guidance	**Medical transition planning** to adult PCP care should begin at age **16-17** **Implementation** of Medical transition plan should occur at **age 18+**
SCREENINGS	Bright Futures Pediatric Screenings by Age	Screenings recommended at various ages throughout the life course. Refer to Bright Futures Guide.
APPLY FOR APPLE HEALTH	Applying for Apple Health Washington Health Plan Finder	Ensure your client has applied for Apple Health at any age throughout their life course.

MEDICAL DIAPERS 3+	Medical Diaper Authorization	Medical diapers are available through HCA for those who have a medical prescription from their provider using the diagnostic code for bowel and bladder incontinence and are **over the age of 3.** See **Medical Equipment and Supplies** Billing Guide
EARLY HEAD START	Early Head Start	See the Early Head Start description in the Systems of Care section
HEAD START	ECEAP and Head Start Head Start	See the Head Start Description in the Systems of Care section
EARLY SUPPORT FOR INFANTS AND TODDLERS (ESIT) 	Early Intervention Services ESIT Transition	See ESIT description in the Systems of Care section. IMPORTANT: This is a crucial transition period for CYSHCN who are receiving ESIT services. For those that are still interested or in need of continued support **after age 3**, ensuring CYSHCN are connected to special education services after aging out of ESIT is an important role of the CYSHCN coordinator. See the Referral Recommendations section for specific timelines
FIRST STEPS	Infant Case Management First Steps and Infant Case Management Provider Directory	The **First steps** program supports low-income pregnant persons with access to health and social services. For CYSHCN and their families, access to **the Infant Case Management program** may be helpful. This service is available anytime after maternity support services end, (generally **3 months**) and may last up to the last day of the month of the baby's **first birthda**y.
SPECIAL EDUCATION	Special Education Overview Early Childhood SE Secondary Transition Transition Planning Resources	See Local School District description in the Systems of Care Section See Childcare/Education description in the Systems of Care Section IMPORTANT Special education services become available **at age 3**. This is a **crucial point of transition for CYSHCN** who are enrolled in **ESIT services** prior.
ECEAP	ECEAP	See ECEAP in the Systems of Care section. This service is available to those **3-4 years** old
VOCATIONAL JOB TRAINING PROGRAMS	DVR School Transition Counselor DVR Overview Page DVR Guide to Services Pathways to Employment	DVR has vocational rehabilitation counselors assigned to each high school in the state **Eligibility**: This includes students within the special education system, as well as youth within the general education system. Students and youth with disabilities who are transitioning from state and local juvenile

	Transition Planning Toolkit (Highschool, work, life, PAVE) HCA Workers with Disabilities	rehabilitation institutions and community programs also may be eligible for DVR transition services.

Appendix

Health Homes and CYSHCN

What is a Health Home?

The Washington State Health Home program is dually supported with partnering agencies Health Care Authority (HCA) and the Department of Social and Health Services (DSHS). This program provides **person-centered, accessible, and frequent case management** at the location of the client's choosing. This service has no time limit and is available for as long as the client would like to remain engaged.

Client eligibility is determined based on a **PRISM score of 1.5 or higher**, and clients are automatically enrolled into the program if they meet this threshold. Because PRISM scores are based on health system utilization, adults are disproportionally represented in the patient population served due to increased time of health system connection. However, **many CYSHCN families are eligible for this program and can benefit greatly** from the accessible case management provided without limit.

Examples Types of Support Offered

Care Coordination: provider referrals, program enrollment, school connection, mental health resources, transitional care, etc.

Resource Support: transportation, housing, nutrition, respite care, etc.

Case Management: Goal setting, Shared Plan of Care support, motivational interviewing, Health action plan development

How can your clients participate?

Clients will be automatically enrolled into the Health Home program if they have a PRISM score of 1.5 or higher. If you believe that your client has conditions and health system exposures that would qualify them and a PRISM score that is close to eligibility, you can contact the Health Home program team to request for your client to be enrolled. They can be reached at healthhomes@hca.wa.gov

Is becoming a Health Home Provider right for your agency?

Deciding if the Health Home program is the right decision for your agency is dependent on several variables. The CYSHCN program at DOH as well as the Health Home program coordinator at DSHS would be happy to meet with you individually to discuss things to consider. The following are factors to begin your consideration:

Reimbursement Rates: The Health Home program offers a tiered reimbursement rate depending on the type of case management offered (initial vs follow up visit). In addition, the MCOs offer varying rates that are not disclosed publicly. MCOs will disclose their rates to participating agencies in private

meetings. The following is a publicly disclosed document with a suggested range of reimbursement rates.

- Managed Care Organizations: When participating with the Health Home program, each participating agency will need to partner with at least one MCO. It will be important to consider which MCOs are most commonly utilized in your patient population and ensure that you select at least one MCO that can serve a significant number of your clients.

- Reporting Platforms: A certain amount of client reporting is contractually required for all Health Home participating agencies. This reporting is done on a web-based platform that is unique to each MCO. If an agency partners with more than one MCO, they will need to report participating client data into more than one platform. The additional administrative time and training needed to be compliant with reporting requirements should be considered.

- Client Caseload Volume: In order to be financially viable, Health Home participating agencies will typically need to have a monthly client caseload of at least 50 people if Health Home is the single funding source for the program. This client caseload number can be lower if supplementary funding sources are braided into the program work.

- Available Staff: There are a variety of providers that can offer case management services, frequently social workers and community health workers are utilized for case management activities, and clinic based administrative staff support the client reporting work. This model is not a requirement of the program but has demonstrated success with existing users. Various staffing models are available to ensure financial viability unique to the needs of the participating agency.

Additional Resources

Health Home Service Provider Locator

Health Home and HCA

Client Eligibility Tool

Inclusive Language Reference

Inclusive Language Reference Document

Although there is not a monolithic language style preference shared across all the people who have a disability, it remains important to use respectful and inclusive language when communicating with or talking about people with disabilities.

Foundations:

- Remember that it is possible for two people with the same diagnosis or circumstance to feel completely differently about their disability.
- Transition from assigned genders such as he/she to using the term "they".
- A general rule of thumb is to avoid terms that "connote pity".
- Two major linguistic preferences:
    - **People-first language** "People with disability". Commonly used to reduce dehumanization of disability and CDC recommended. This emphasizes the person first not the disability.
        - Ex: A person who uses a wheelchair not wheelchair bound
    - **Identity first language**- "Disabled people". Used to celebrate disability pride and identity. Autistic and Deaf or Hard of Hearing advocacy communities have celebrated this language.
        - Unanimity on which is more respectful, can use interchangeable to acknowledge and respect multiple preferences.
- Acknowledging both language preferences at the beginning of documents and explaining which is chosen for the document can validate both perspectives.
- Shying away from acknowledgement can reinforce idea of disability as something of shame
    - ***Note:** *The word special is particularly entrenched because it can be used as a euphemism but also may be utilized technically (e.g., "special education"). There is a desire to move away from this word. However, there is also acknowledgement that terms such as "special needs" are uniquely situated to introduce non-disabled parents and loved ones of children with disabilities to a rich and complex world of disability access, inclusion, accommodation rights, and systems of support*.
- **Do not use language that suggests the lack of something.**
- **Emphasize the need for access not the disability.**
- **Do not portray people with disabilities as inspirational only because of their disability.**
- It is only appropriate to refer to someone as a patient in a medical setting, regardless of their disability status.
    - Not all disabilities are illnesses and not all people with disabilities are patients.

- Use “deaf and hard of hearing community” when referring to the community of people with all kinds of hearing loss. Use capitalized “Deaf” when referring to Deaf culture and the community of Deaf people. Use “partial hearing loss” or “partially deaf” for those who have some hearing loss.
    - The term “hearing impaired” is not recommended.

Avoid	Alternative
crazy, mad, psycho, lame	person with mental health condition/illness*
defect, disorder, disease, illness	person with a congenital disability, person living with congenital disability, condition, diagnosis (neutral language)
normal, healthy, able-bodied	non-disabled
condescending language like differently-abled, challenged, handicapable, etc.	Person with a disability
Handicapped	“person with a disability” or “disabled person”
*Special Needs	“Functional needs” is preferred. The term “special” in connection to people with disabilities runs the risk of euphemistically stigmatizing disabled people’s differences. The notion is that despite differences in everyone’s needs, referring to the needs of only disabled people as “special” carries an infantilizing connotation.
High Functioning/Low Functioning	Low support needs, high support needs
Nonverbal	Non-speaking
Suffers from/victim of/stricken with	“they have/are living with muscular dystrophy” is preferred to “they suffer from muscular dystrophy.”
Wheelchair-bound	Use “wheelchair user” or “person who uses a wheelchair.”
Overweight	If weight is not clinically relevant, there is no reason to mention it in discussion or writing.

	• Example: no reason to mention/chart BMI or weight in a patient being seen for strep throat. • Example: if a patient requires a weight-based dose of medication, stating their weight is necessary, but terms like obesity or overweight are still not useful.
Underweight (These are imprecise and clinically irrelevant terms)	Person at higher weight or lower weight Person in a lager body or smaller body Objectively state the person's weight in pounds or kilograms
Obese Obesity Morbidly Obese Grade Obesity *(These terms all pathologize a person based on their size alone and are stigmatizing and contribute to bias)* Person with obesity	If BMI must be stated use number only, not category Consider asking how the individual self-identifies and their preferred language: • How do you prefer to talk about weight and body size? • What language do you use to talk about your own weight and body size? There are communities using terms like fat, including subcategories like small fat, mid fat, etc. but it should not be assumed that the patient is okay with these terms. When referring to body size, Person-First Language medicalizes and pathologizes a person based on their size alone, which is not supported by evidence and contributes to stigma and bias against larger patients.
Curvy Fluffy Chunky Heavy Fat	There are other terms such as straight size, mid-size, plus size that are used more often in clothing industry but these are less appropriate for a medical setting.
Patient is too obese for our MRI/CT/Gowns etc.	Our equipment (whatever it is) is not adequate for patients at this size.

Get on the scale please Time to be weighed	If using opt-out weight policy: • Would you like to be weighted today? • Offer blind weigh in an do not state weight without permission. Consider an opt-in weight policy: Only ask to weigh patients when specifically needed for their condition (i.e. heart failure, weight-based medication dosing, eating disorder treatment). If not required, don't weigh anyone unless requested by patient.
Good/bad foods Healthy/ unhealthy foods Junk/processed food Clean/ limited processed foods Convenience foods Cheat foods/ day Indulgent Guilty pleasure Dangerous foods *(Many of these terms are not medically relevant and are taken from diet culture)*	Instead of assigning any moral value to a person's food, behavior, or actions; use neutral language. Try to use terms that reflect specific things about the food being discussed: • More/less nutrient dense • Higher/lower in fat, saturated fat • Higher/ lower in sugar • Higher/lower in salt • Whole fruits and veggies • Whole grains vs refined grains • High/lower in fiber All foods fit: healthy means different thing for all bodies, so no one food is healthy or unhealthy for everyone. Food does not have moral value: food choices can impact how your health or how you feel, but food choices do not make you a good/bad person: • This food was nourishing to my body while that food was nourishing to my soul.
• Healthy and unhealthy food • Bad food and good food • Always, sometimes and anytime foods	• Balanced eating • All foods fit • Avoid labeling foods good/bad

	• Explore food neutrality
Exercise	Body movement, Physical activity, Joyful movement, Active play
There is no consensus on one “best” term to use when referring to a person’s size or weight. Some terms are preferred for some people, but not for others considering the origins, histories, and their own experiences with the words. We acknowledge all of these are umbrella terms that lump unique individuals into one group. When possible, we will avoid generalization and use the terminology preference of the individual. When possible, we will ask the person or group which term they prefer.	
Mental Retardation	Use “person with an intellectual disability.”
Rethinking "Vulnerable" and Related Terms	**Suggested Alternatives (alphabetical order only)**
At-risk	Groups who experience a disproportionate burden of [poor health]
Disadvantaged	Groups who experience health inequities
Susceptible	Priority population
Underserved	Structural vulnerability / Structurally vulnerable
Vulnerable	Name the source(s) of vulnerability: bias, cis-hetero domination, discrimination, health inequity, misogyny, oppression, policy, racism, segregation, white supremacy, etc.

When Discussing Equity

When referencing disparities emphasize the value of equal opportunity for health that reducing disparities contributes to.

Consider using the following:

- Systemic and social inequities for increased risk of illness
- Avoid implying responsibility for increased risk of adverse outcomes
- Social determinants of health for health disparities context
- Consider lack of inclusive infrastructure when considering resource allocation

Key Principals:

Avoid dehumanizing language. **Use person-first language instead**. Describe people as having a condition or circumstance, not being a condition. A case is an instance of disease, not a person. Use patient to refer to someone receiving treatment.

Avoid use of the terms such as vulnerable, marginalized, and high-risk as adjectives. These terms can be stigmatizing. These terms are vague and imply that the condition is inherent to the group rather than the actual causal factors.

Avoid	Alternative
Underserved people; the underserved; hard to reach; the **uninsured**	People who are underserved; people who are medically underserved; people without health insurance; **underrepresented** *Note: "Underserved" relates to lack of access to services, including healthcare. Do not use "underserved" when you really mean "disproportionately affected." Use person-first language.*
Homeless people; the homeless; transient population	People experiencing homelessness; persons experiencing unstable housing/housing insecurity; persons who are not securely housed
Poverty-stricken; the poor; poor people	People with lower incomes; people/households with incomes below the federal poverty level; people with self-reported income in the lowest income bracket (if income brackets are defined); people experiencing poverty (do not use "underserved" when meaning low SES) *Note: "People with lower levels of socioeconomic status" should only be used when SES is defined (e.g., when income, education, and occupation are used as a measure of SES).*
High-risk people; high-risk population; vulnerable population; priority populations	People who are at increased/higher risk for [condition]; people who live/work in settings that put them at increased/higher risk of becoming infected or exposed to hazards; populations/groups disproportionately affected by [condition]; populations/groups highly affected by [condition]
Pregnant women; mothers-to-be; expectant mothers	Use terms that are inclusive of all gender identities: Pregnant people; parents-to-be; expectant parents
Rural	People who live in rural/frontier areas; residents/populations of rural areas; rural communities
Referring to people as their race/ethnicity (e.g., Blacks, Hispanics, Latinos, Whites, etc.) • Indian (to refer to American Indian); Eskimo; Oriental; Afro-American; Negro; Caucasian • the [racial/ethnic] community (e.g., the Black community) • non-White (used with or without specifying non-Hispanic)	Preferred terms for specific racial/ethnic groups: • American Indian or Alaska Native persons Asian persons Black or African American persons Hispanic or Latino persons Native Hawaiian or other Pacific Islander persons White persons People who identify with more than one race/ethnicity; people of more than one race/ethnicity *Note: Black and White should be capitalized. Note: "American Indian or Alaska Native" should only be used to describe persons with different tribal affiliations. Otherwise, identify persons or groups by their specific tribal affiliation.* Preferred terms for groups including 2 or more racial/ethnic groups:

	• People from some racial and ethnic minority groups • People/communities of color Note: Only used to collectively refer to racial and ethnic groups other than non-Hispanic White; be mindful to refer to a specific racial/ethnic group(s) instead of this collective term when the burden and experience of disease is different across groups.[22, 23]
Medical and Insurance Based Language: Obesity/Obese, Overweight, Extreme Obesity, Pediatric Obesity	Person-first language is preferred: • Unhealthy weight • Gaining too much weight for age/height/health • Body Mass Index • Persons with Obesity *Teaching patients and families about the difference:* *Hampl S, et al. 2023.Pont, et al 2017. Kirk, et al 2022.*

CDC Reference Pages:

Disability Inclusion

Disability and Health

Reaching People with Disabilities through Health Communities

CYSHCN Managed Care Organization Referrals

In Washington state, there are five Medicaid Managed Care Organizations (MCOs) who are contracted to deliver Integrated Managed Care (ICM) services which include **Care Coordination and Case Management** for eligible clients. Both Care Coordination and Care Management are administered as the MCO identifies clients who would benefit, but **CYSHCN coordinators can also request and refer Care Coordination and Case Management services** for their CYSHCN clients.

Care Coordination Activities (CC):

- Focus on short term or intermittent needs
- May be provided by unlicensed/nonclinical staff
- Access to care/services addressing social needs
- Improve clinical outcomes
- Increase self-management skills
- Voluntary

Case Management Activities (CM):

- Focus on longer term support (52pprox.. 3-6 months engagement)
- Provided by licensed/clinical staff
- Assist members in managing complex healthcare needs
- Goal setting based on individual's priorities
- Integrated care planning with member consent
- CM services are voluntary, and must have member/guardian consent to provide CM

Managed Care Plans

Apple Health Managed Care Service Map

Wellpoint (Previously known as Amerigroup)

Community Health Plan of Washington

Coordinated Care of Washington

Molina Healthcare of Washington

UnitedHealthcare

***Note that Coordinated Care of Washington is also contracted as the **single managed care plan** to serve the **integrated foster care** contract statewide, including foster children and youth, adoption support, and alumni of foster care

Contacting MCOs for Referrals and Support

There are several ways to connect with MCOs on behalf of your CYSHCN client

1. You can reach out the MCO emails below to request Care coordination and/or case management. Please see the table below as the process may vary for each MCO.
2. You can reach out to the MCO CYSHCN coordinators in the CYSHCN MCO Coordinator Contact list
3. CYSHCN Care Coordinators can reach out to the direct MCO central email managed by HCA. This contact is great for general MCO questions or if you need additional support or clarity about which MCO to reach out to and what services to request. The email is HCAMCPrograms@hca.wa.gov .

MCO Point of Contact Information

	General Contact Information	Referral Information
Wellpoint (Amerigroup)	cmrefwash@wellpoint.com	Use contact to send a request for care coordination planning and case management
Coordinated Care of Washington	CareManagement@coordinatedcarehealth.com	Use contact to send a request for care coordination planning and case management
Community Health Plan of Washington	CareMgmtReferrals@chpw.org	Use contact to send a request for care coordination planning and case management
Molina Healthcare of Washington	MHW_PediatricCM@molinaHealthCare.com	Molina has a **formal** referral process, with a referral form below to send referrals, questions, etc. : Molina Form for Referral for Care Management Services For specific member/family questions/concerns, aside from routine referrals, reach out to Michelle Hill: michelle.hill2@molinahealthcare.com
United Healthcare	wa_carecoordinationrequests@uhc.com	Use contact to send a request for care coordination planning and case management

MCO CYSHCN Coordinator Contacts

Agency	Name	Phone Number	Email
Wellpoint (Amerigroup)	Derek Steele	206-482-4362	derek.steele@wellpoint.com
Wellpoint (Amerigroup)	Charla Morrow	*	Charla.Morrow@wellpoint.com
Wellpoint (Amerigroup)	Terri Brazelton	207-274-0392	Terri.brazelton@wellpoint.com
Wellpoint (Amerigroup)	Abigail Osborne-Elmer	509-405-0204	abigail.osborne-elmer@wellpoint.com
CHPW	Ganita Musa	206-291-8073	Ganita.Musa@chpw.org
CHPW	Megan Boardman	206-515-7947	Megan.Boardman@chpw.org
Coordinated Care	Sherry Bennatts	253-442-1543	sbennatts@coordinatedcarehealth.com
Coordinated Care	Keith McNeal	253-240-3111	Keith.McNeal@coordinatedcarehealth.com
Coordinated Care	Suzie Tallar	253-442-1527	Suzanne.E.Tallar@coordinatedcarehealth.com
Coordinated Care	Sydney L. Doherty	253-290-2878	Sydney.L.Doherty@coordinatedcarehealth.com
Molina	Kelly Anderson	425-375-0809	Kelly.Anderson@molinahealthcare.com
UnitedHealthcare	Kate Naeseth	763-321-2358	kate.naeseth@uhc.com
UnitedHealthcare	Cassie Mitson	952-202-9122	cassie_mitson@uhc.com

Recommendations Requesting MCO Care Coordination & Case Management:

- **Discuss with CYSHCN and family prior to referral and get consent prior (if possible)**
- **Send a secure email to the client's MCO to request care coordination.**
    - Emails from local health jurisdiction identify the sender as a public health employee and are HIPAA-compliant
- **Specify [CYSHCN – Request for Care Coordination or Case Management] in the subject line and provide the following information within the request:**
    - Individual's name
    - Individual's ProviderOne ID (9-digit number ending in "WA")
    - Individual's date of birth
    - CYSHCN Care Coordinator's name and contact information

- Details about the individual, including current services (if known) and the reason for the request for care coordination
- Client or legal representative's contact information
    - *Indicate that the client or their representative requested care coordination*
    - *Indicate if the MCO should contact the CYSHCN Coordinator prior to contacting the individual or their representative*

MCOs and SSI Application Support

MCOs are able to support CYSHCN and their families with **SSI applications**. The procedure would still be to request Coordination support, with the MCOs via one of the three recommended mechanisms; the MCOs contract out the SSI application support. This is important to share with families right away. A company called Centauri Health Solutions will reach out to families for support in their SSI applications if the MCO identifies this need. Because Centauri will be calling families asking for personal health information for the CYSHCN in the household, it is important for families to be made aware of this partnership to build trust and partnership with this resource.

CYSHCN Care Coordinators may share a Centauri FAQ document with CYSHCN families in order to prepare and educate on them on the resource.

Diagnostic and Treatment Funds (Dx/Tx)

What are Diagnostic and Treatment Funds?

Diagnostic and Treatment funds are small pot of funds the Children and Youth with Special Healthcare Needs (CYSHCN) program has available for **medically necessary services/equipment** beyond the scope of routine care common to most children. Services/equipment include those not **covered by any other funding source** (ex: Medicaid, Developmental Disability Administration, Managed Care Plans, etc.) Dx/Tx funds align with the Washington Administrative Code (WAC) 246-710-050. The state CYSHCN program has **allotted $5,000.00 per federal fiscal year** to disperse to CYSHCN and their families upon request from partners.

Who is Eligible to Access the Funds?

These funds are accessible to **Children and Youth with special healthcare** needs who meet **all** the following criteria:

- The request is from a qualified provider
- The service/resource is considered **medically necessary** by the qualified provider
- The request is for a client who has AppleHealth Coverage (Medicaid)
- Medicaid, MCOs, and other potential payers have denied the service/resource request, **AND** potential payers have rejected an appeal for the denial
- All other potential payers have been sought without the success of coverage for requested funds

How is "Medical Necessity" defined?

The WAC 182-500-0070 define it as the following: ***Medically necessary*** *is a term for describing requested service which is reasonably calculated to prevent, diagnose, correct, cure, alleviate or prevent worsening of conditions in the client that endanger life, or cause suffering or pain, or result in an illness or infirmity, or threaten to cause or aggravate a handicap, or cause physical deformity or malfunction.*

How do you request Dx/Tx Funds?

If you believe your client may be eligible to request Dx/Tx funds and no other source of client funding support has been found, you can reach the Dx/Tx coordinator Khimberly Schoenacker at Khimberly.Schoenacker@doh.wa.gov. Please include your preferred times and forms of communication to be reached at.

Please note that our program is required by state mandate, to ensure no other funding sources are available for the requested services/equipment. The Dx/Tx coordinator can also provide support in identifying Medicaid and other potential funding sources available to support your client. If your client is eligible, a **Health Services Authorization form** will be provided to you by the Dx/Tx coordinator for submission to the CYSHCN program for eligibility review. Reviews may take up to 4 weeks to complete. If

a client is identified as ineligible, potential existing funding and resource sources will be offered for consideration.

Other Resources to consider:

CYSHCN Manual Section 6000: Authorization and Payment

Key Community Resources: Washington State Medical Home Partnerships Project

Shayla's Resource List

Managed Care Plan Map

Wellpoint Medically Intensive Children's Program

Community Health Plan of Washington: Coordination Program

Coordinated Care: Care Coordination and Disease Management

United Healthcare-Community Plan

Molina: Integrated Case Management

Developmental Disabilities Administration Eligibility and Services Guide

Center of Parent Excellence (COPE) Project-Behavioral Health Navigation Support

Washington State Department of Children, Youth, and Families: Community Resources

Washington Grants for Autism and other Special Healthcare Needs

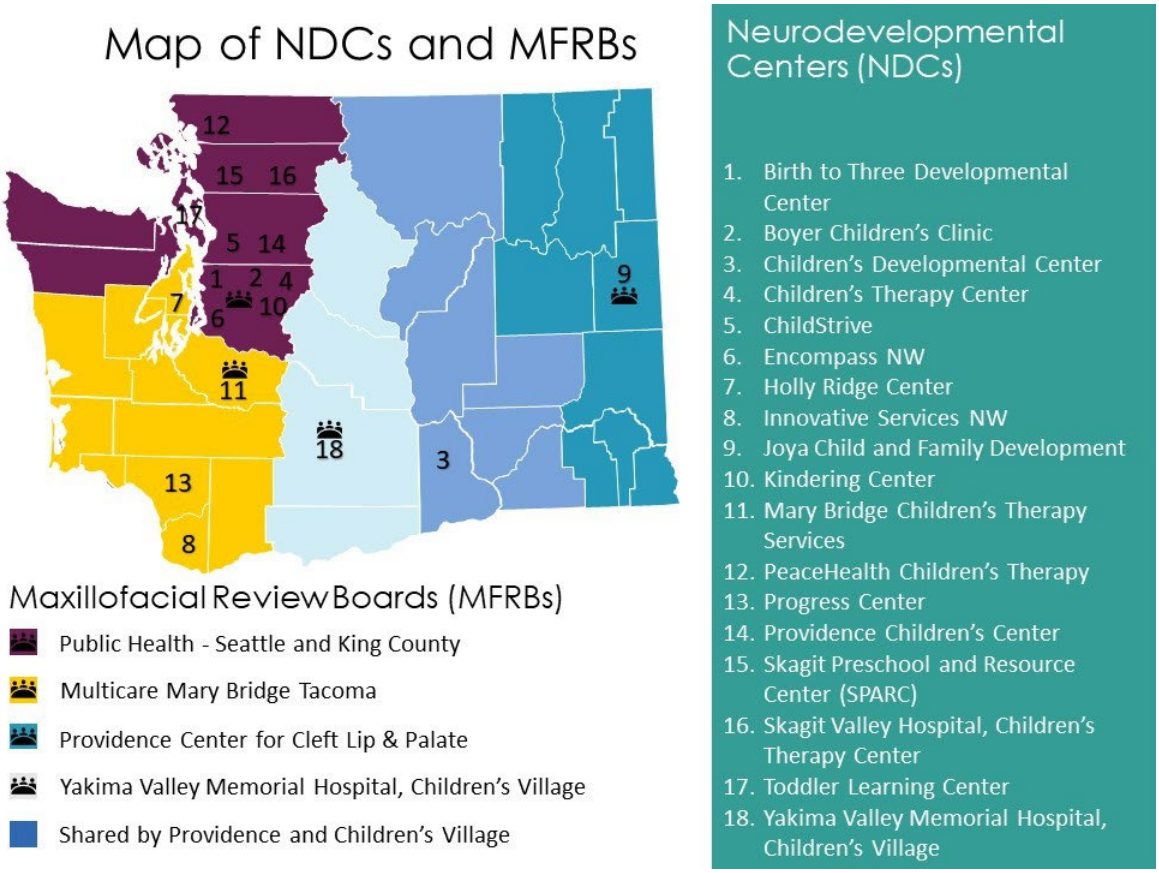
Partnerships for Action, Voices for Empowerment (PAVE)

Lifespan Respite

Needy Meds

United Healthcare Grant

Map of Neurodevelopmental Centers of Excellence and Maxillofacial Review Boards



Additional Helpful Resources Links

Boston Children's Hospital Care Coordination Measurement Tool

Care Coordination: Empowering Families, A Promising Practice to Facilitate Medical Home Use Among Children and Youth with Special healthcare Needs

Care Coordination Tier Level Assessment Tool

Understanding the Medical and Health management Support Needs of Each Child/Family

Care Coordination Tier Assignment Tool, Version 1.0 Health Care Home Initiative

CHQC Massachusetts Child Health Quality Coalition: Care Coordination Strengths and Needs Assessment Tool

Lucile Packard Foundation for Children's Health: Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs

Youth with Special Health Care Needs: Transition from Pediatric to Adult Health Care

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