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 Healthcare 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 care-giving 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 this Children and Youth with Special Health Care Needs (CYSHCN) Care Coordination Toolkit is to provide CYSHCN coordinators a comprehensive consolidation of resources and guidance across the various systems of care available to CYSHCN in Washington state. 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 tool kit: Washington Systems of Care for CYSHCN, Shared Plan of Care: Resource Referral Guide, and CYSHCN Life course Transitions and Eligibilities. CYSHCN 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 CYSHCN care coordinators and the clients that they serve, but is also available for distribution to other pertinent CYSHCN partners and families.

The Role of the CYSHCN Coordinator

The responsibilities of the CYSHCN coordinator varies at each local health jurisdiction (LHJ) depending on the capacities of each agency. However, the role all coordinators play across the state is to serve as the
support and advocate for CYSHCN and their support systems from birth to age 18\(^1\). There are various programs and services CYSHCN are eligible to **age into and out from** throughout their life course, and families of CYSHCN juggle many responsibilities during that time. Evidence\(^1-13\) has demonstrated CYSHCN and their families benefit greatly from wrap-around support and services; this ensures their child has access to the services and resources they need to “(1) develop and realize their potential; (2) satisfy their needs; and (3) develop the capacities that allow them to interact successfully with their biological, physical, and social environments.”\(^1\) CYSHCN Coordinators support this need by serving as an accessible point of contact for CYSHCN and their support systems, that offers guidance, resources, and referrals.

**Warm Hand Off and Referrals**

CYSHCN coordinators often wear many hats within the agencies they serve, it is not feasible for 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 off’s” and referrals** depending on the identified needs from the family.

**What is a “warm hand off?”**

A warm hand off is the process when two service providers working with CYSHCN connect before the child/ CYSHCN age out of a service. This practice allows service providers to plan with each other and the CYSHCN to make sure they have the needed resources and support and have plans in place for the next steps. This connection is critical to improve the quality of care for CYSHCN in our state.

Often without this “warm hand off” CYSHCN and their support systems are not aware of services they are eligible for after they have aged out of a resource. And CYSHCN can fall through the “cracks” of care. Dropping out of the systems of care while the CYSHCN still have a need has harmful impacts on their biopsychosocial health and their support systems.

**Leveraging key resources – removing barriers to engagement**

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

**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 **15 languages**.

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\(^1\) In some cases CYSHCN may receive support to age 21
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 handoffs between families and local CSYHCN coordinators. You can refer to and find an ESIT coordinator 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. CYSHCN coordinators can ask the FRC to share resources with the family and offer guidance on how to a CSYCHN coordinator may support them and how they can get in touch.
  - 2-3 months before a family’s ESIT service ends, 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 support systems. This can help identify what success may look like for CYSHCN. 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. MOU link

- 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 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 coordinators to know and use the 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 as 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, and support resource allocation and support to 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 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 didn’t align with their needs, this way you can adjust and reframe accordingly.
- Position your body language 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 linguist 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 families 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 the Healing Centered Engagement, which recognizes each CYSHCN’s diverse needs and preferences.

If you would like more information around specific language that should be avoid and included, please see a detailed fact sheet that 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 duplicating your 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. Many of these partners may send referrals to LHJs. We encourage LHJs to know these partners and 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. 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 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).
Figure 1. CYSHCN Systems of Care Map

<table>
<thead>
<tr>
<th>Acronym Key</th>
</tr>
</thead>
<tbody>
<tr>
<td>CYSHCN: Children and youth with special Healthcare Needs</td>
</tr>
<tr>
<td>WISe: Wrap Around Intensive Services</td>
</tr>
<tr>
<td>SMART: School and Medical Autism Review Team</td>
</tr>
<tr>
<td>MCO: Managed Care Organization</td>
</tr>
<tr>
<td>DDA: Developmental Disabilities Administration</td>
</tr>
<tr>
<td>CHW: Community Health Worker</td>
</tr>
<tr>
<td>MFRB: Maxillofacial Review Board</td>
</tr>
<tr>
<td>ECEAP: Early Childhood Education and Assistance Program</td>
</tr>
<tr>
<td>ADA: Americans with Disabilities Act</td>
</tr>
<tr>
<td>IDEA: Individuals with Disabilities Act</td>
</tr>
<tr>
<td>NCLD: National Center for Learning Disabilities</td>
</tr>
<tr>
<td>IEL: Institute for Educational leadership</td>
</tr>
</tbody>
</table>

CYSHCN Systems of Care Map

Aging and Long-Term Support Administration (ALTSA)
Department of Services for the Blind
Accountable Communities of Health (ACH)
Office of Superintendent of Public Instruction (OSPI)
Department of Health (DOH)
Developmental Disabilities Administration (DDA/DSHS)
Department of Children, Youth and Families (DCYF)
Healthcare Authority (HCA)

State Social/Health Programs
Local School District
Within Reach/Help me Grow

WISe Team
Maxillofacial Review Boards (MFRB)
Autism Centers of Excellence
Neurodevelopmental Centers of Excellence

WISE Team
Maxillofacial Review Boards (MFRB)
Autism Centers of Excellence
Neurodevelopmental Centers of Excellence

Care Coordination
Health Services

Family Support
Childcare Education
Community Engagement

The Arc
Parent to Parent
Father's Network

Informing Families
Washington Mental Health Referral Service
Inter-agency Coordinating Council (Local)
Washington Connections
PAVE

language Access Services
Accessibility
Culturally Competent Care
Disability Justice
Inclusion and Belonging

Interpreter Services (HCA)
Out-of-Home Services
Assistive Technology
Open Doors
DDA Tribal Liaison

Equity and Cultural Humility

Transportation (HCA)
Section 504
Tribal Vocational Rehabilitation Services
EthnoMed

ADA
IDEA
NCLD/Y
IEL

Rooted in rights
Special Olympics

Title VI of Civil Rights Act (language access)
DD Ombuds
Office of Special Education Ombuds

Health Homes
MCO Care Coordination
Family Resource Coordinator
DDA Case Managers
CHWs

CYSHCN & MFRB Coordinators

ADAP: 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\textsuperscript{2,14-21}. 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 (RD) who specializes in CYSHCN specific nutrition may be a helpful resource for your client. The Washington state Nutrition Network provided a variety of resources to find both feeding teams and specialized dietitians in your area. In addition, some Neurodevelopmental Centers of Excellence (NDCs) include RDs and feeding teams within their center. Check with your local NDC to find if that service is available locally, and refer to the Nutrition Network website for resources and 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-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 often have family resource coordinators and various other therapy providers all in one place for families. 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 necessary for children to obtain an autism diagnosis. A COE could be any medical practice, psychology practice, multidisciplinary assessment team, or indivudual provider who has either received COE training through the 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) are 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 capacities. Pediatric primary care providers partner with schools, early intervention agencies, and families using the SMART tool 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 therapeutic support they require. The following are a list of some important providers to keep in mind when considering the needs of your CYSHCN client:

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, in schools, NDCs, and in specialized medical clinics.

Occupational Therapist (OT)- OTs may support children who experience a health challenge such as cognitive, physical, or sensory, that impair 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 (RD)- RDs may support children by performing nutritional assessment 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 Healthcare Authority and is voluntary for all Apple Health clients. WISe provides intensive mental healthcare 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 for mental health services 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) are located in each region in Washington and serve as a multidisciplinary team for 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, facilitate visits as necessary, and summarize 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. Care 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 handoff to 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 through the Department of Children, Youth, and Families (DCYF) that are eligible for Apple Health (fee-for-service Medicaid), specifically for 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-Citizen and existing enrolled clients (prior to April 1, 2016) in the Health Care Authority (HCA), Medically Intensive Children’s Program (MICP).

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 PRISM score. Utilization of the system may be difficult 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 for 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.

MCO Care Coordination

Managed Care Organizations (MCOs) include 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 Communication Network Meeting (pg. 31-48). As indicated by the graphic below, there are overlapping activities between CYSHCN care coordinators and MCO Care Coordinators: both may connect their clients to resources needed, may partner with other pertinent systems or care, and may address health and safety needs.
Because of these overlapping duties, if the CYSHCN care coordinator deems it appropriate, they may request to partner and collaborate directly with the MCO 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 care 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 these existing resources; the program is available to offer guidance and resolution.

![Figure 2. Created by Kathleen D. (HCA)](image)

**Family Resource Coordinator**

**Family Resource Coordinator (FRCs)** - For CYSHCN enrolled in Early Support for Infants and Toddlers (ESIT), a Family Resource Coordinator is assigned and made available for case management support. An ESIT FRC can help with resource referrals, supporting the goals of the family, and ensuring warm handoffs 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 the CYSHCN are enrolled in ESIT, as well as receiving the rights and procedural safeguards for the early intervention program. The CYSHCN coordinator can ensure that eligible clients are enrolled in ESIT and that they have been
connected to their FRC. Prior to a child aging out of ESIT services, the CYSHCN coordinator should connect with the child’s FRC to ensure a **warm hand off** and prevent gaps in care. You can refer to and find an ESIT coordinator through the [ESIT Referral Contacts by County and School District](#).

**DDA Case Managers**

A CYSHCN client who is an **enrolled** client of the Developmental Disabilities Administration (DDA) and is receiving a paid service from DDA can gain support from **Case Resource Managers (CRM)** provided through DDA. Case Resource Managers help clients with access to pertinent resources and DDA services. If your CYSHCN client is a DDA client receiving a paid DDA service and does not have a Case Resource Manager, you can help them fill out a [Service Referral and Information Request](#) or call DDA to request a CRM.

**Community Health Workers (CHWs)**

Community Health workers 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 in locations of their request and can provide a variety of supports ranging from checking blood pressure to resource referral and advocacy. A CYSHCN coordinator can connect with a local CHW through [DOH contacts](#), the [Washington Community Health Worker Association](#), and through some Managed Care Organizations.

**CYSHCN and MFRB Coordinators**

While not all **LHJ CYSHCN Coordinators** will be providing direct services, depending on the needs and capacities of their community, some may offer more coordinating services than others. As a CYSHCN coordinator, it is important to know how to access the [contact information of other coordinators](#). This will facilitate improved collaboration regionally and statewide, as well as preventing gaps in coverage by connecting your CYSHCN client to a new CYSHCN coordinators if they move to a new area. In addition, **MFRB Coordinators** do provide care coordination for clients with oral facial anomalies. If you are connected with a CYSHCN client who would be eligible for MFRB services, but is not yet connected, you can use this webpage to contact MFRB coordinators in Washington state.

**Family Support**

**Community Engagement**

[The Arc](#) of Washington State is a non-profit organization that provides various advocacy and community engagement programs and resources. 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 and support.
Parent to Parent

Parent to Parent (P2P) is a valuable community connection resource for CYSHCN families. CYSHCN families can connect 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 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 your clients have the support. 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 Father’s Network

Washington State Father’s Network can provide community support for those identifying as male CYSHCN parents. The Father’s Network connects male identifying people with each other and offers support for fathers to share their stories and promotes inclusion. You can visit the Washington Father’s Network website for information, contacts for local chapters across Washington, and their regular meetings schedule.

Childcare/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 the Federal Poverty Level. You can find more information in the Poverty Guidelines Resource. Families receiving TANF, SSI or SNAP and children in foster care or children experiencing homelessness are eligible regardless of income. Families can apply for Head Start through their Head Start Locator.

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 women. 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.

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 aged 3 and 4. Some locations offer early ECEAP supporting infants or toddlers younger than 3 years old. The program provides free early learning childcare and preschool and family and parent 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. 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 and friends to meet weekly in a facilitated play 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 with multilingual groups available to join.

Childcare Aware of Washington

Childcare Aware of Washington is a nonprofit organization that facilitates 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. CYSHCN care coordinators can help parents 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 a 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 the CYSHCN has the essential resources, accommodations, and support. School is an important resource connection point for assessments and referrals to multiple resources. Here are a few examples:

- If you need to connect with a local school nurse or health supportive resource, reaching out to the Health Services contact, Annie Hetzel is 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 FAPE resource.
• 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 identifies children who may need evaluation for special education and related supportive services.

Within Reach/Help me Grow/ParentHelp123/AS360
Within Reach/Help me Grow/ParentHelp123/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, use your 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 learning in school, parent and family supports, health and wellness, and more. Pave’s Parent Training and Information (PTI) program is another useful resource for CYSHCN caregivers. This program offers caregivers and providers information about services for CYSHCN ages 0-26. In addition, PAVE offers a program called the Family to Family Health Information Center; this program supports CYSHCN families and providers in finding funding for necessary healthcare services. Family-to-Family offers resources, advice, and a network of partnerships to support healthcare financing needs of CYSHCN and their families. Other Pave programs cover topics such as school age transition, finding funding for healthcare, respite, etc. You can find their trainings on their program page. Pave also hosts Parent to Parent out of Pierce County. You can also connect to Parent to Parent through The Arc of Washington Coordinators.

Informing Families
Informing Families is an educational hub that offers information about CYSHCN transitions through their life course. It also provides information about CYSHCN eligibility, applications for systems of care, news, advocacy, and other resource information. Their educational videos for different CYSHCN transitions and 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. Presentation slides on both the Washington Mental Health Referral Service and PAL can be found on the CYSHCN Communication Network Slide Deck in slides 42-46.

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

WA 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.

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

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 children and youth in an out-of-home dependency through Department of Children, Youth, and Families or Tribal Court and are eligible for fee-for-service Medicaid clients exclusively. In particular this includes the following three 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 healthcare 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. Additional information on the Fostering Well-Being program may be found in the CYSHCN program’s Communication Network meeting slide deck starting on page 31.

Office of Deaf and Hard of Hearing

Office of Deaf and Hard of Hearing (ODHH) is housed withing the Department of Social and Health Services, and provides a variety of supportive services for those that are Deaf, Deafblind, DeafDisabled, Hard of Hearing, Late Deafened and Speech Disabled individuals, 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 Language Interpreter access and guidance.

Department of Health

Washington State Department of Health (DOH) hosts, funds, and facilitates different Public Health interventions, including WIC, SNAP, provider credentialing, and much more! The Children and Youth with Special Healthcare Needs (CYSHCN) program is also housed within DOH. This program is funded by State funds and several grants.

We promote an integrated system of services for CYSHCN and their families. Our services help CYSHCN and their families belong, participate, and thrive in communities with integrated, accessible systems. We support their physical, mental, developmental, social, and emotional well-being. We also provide different supports such as Family Engagement, Nutrition, Mental/Behavioral Health, and consultation. CYSHCN care coordinators can reach out to the CYSHCN program for resources and support. You can also access and distribute our CYSHCN Brochures for Families (available in 15 languages) to your clients.

• The Newborn Screening program is also housed within DOH. The program facilitates and coordinates evaluations, assessments, and payments for newborn screenings. The program has a Parent Resource Page with multilingual education and resources for newborn screenings.
• Universal Developmental Screening (UDS) exists within DOH to support childhood development through regular screenings and help identify developmental milestones. This work helps identify
opportunities that celebrate CYSHCN strengths and addresses areas of concern. UDS also offers parents, providers, and early learning partners access to the Strong Start Screening System. Strong Start is a FREE online system to help track screening records for CYSHCN age birth to 5 that will soon be available across the state.

Developmental Disabilities Administration

Developmental Disabilities Administration (DDA) is a Washington state system of care within the Washington State Department of Social and Health Services (DSHS). DDA provides support and fosters partnerships to empower people with 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.

DDA Eligibility Flow Chart

The Washington State Department of Children Youth and Families

The Washington state Department of Children Youth and Family hosts a variety of programs to support families. Their programs include services like 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 handoff” when CYSHCN age out of this program. It is vital for you to connect with FRCs and be available as a “warm handoff” support when CYSHCN and their family age out of ESIT. You can also support CYSHCN transition into other programs and systems of care. You can refer to and find an ESIT coordinator through the ESIT Referral Contacts by County and School District.

Healthcare Authority

Healthcare Authority (HCA) coordinates and distributes health care insurance and services for over 1/3rd of 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. ACH 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) is the primary Washington state agency overseeing the public K-12 education. OSPI collaborates and guides 295 public school districts and 6 state-triable education schools. The state’s Special Education is also housed within OSPI. 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 to needed educational support. 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 a contacts your local school districts for appropriate referrals and coordination between you and the school system.

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 right 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 the Department of Children Youth and Families (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 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 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 connected to their DDA case manager for assistive technology access. In addition, 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 rich consolidation 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: Transportation Services (non-emergency) and a Disability Parking Placard are two frequently requested services. Non-emergency Transportation Services are provided and coordinated through the Healthcare Authority (HCA); HCA provides accessible transportation via public bus, taxi, wheelchair van, airplane, and ferry tickets. In addition, CYSHCN parents my find their 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
- 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 Washington State 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.

In addition, the Washington Department of Transportation offers discounted fares for those who have a qualifying disability. They offer reduced fares for things such as reduced Ferry tickets for those that are able to present a disability verifying identification to the ticket seller when purchasing.

King County Metro also offers reduced fare permits for those with a qualifying disability, and the application can be completed online or in person. Yakima, Spokane and other counties also offer their own disability reduced fare programs.

Culturally Competent Care
Open Doors
Open Doors provides culturally and linguistically relevant services and education to diverse families of persons with developmental and intellectual disabilities. They offer a variety of programs, resources, and events primarily in the King County area. They serve immigrants, refugees, and families of color. 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 with access to tribal services to their tribal liaison for additional support.

Tribal Vocational Services
Tribal Vocational Services is offered by the Washington State 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 cultures, 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 Act

*Individuals with Disability 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, 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 such as academic, social, behavioral or something else, 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 Civil Rights Act**

*Title VI of 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 safe and quality centered 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

Washington State [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

10 [Principals of Disability Justice](#) are important foundations for both 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 a particular centralizing of artists that 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. In addition, 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 deficient as they are, and CYSHCN have resources available to them in order to align with that they define as success.

Inclusion and Belonging

National Center for Learning Disabilities

NCLD-National Center for Learning Disabilities 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 as their families such as 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

IEL- Institute for Educational Leadership

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 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. The 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 Special Olympics movement, and create inclusive communications. 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 tool -- COIN Birth to one Roadmap, and is 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 in. 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
### AREAS OF SUPPORT

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<td><strong>Smart Teams</strong></td>
<td>HealthPoint allows users to search for providers and specialists based on the language access needs</td>
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<tr>
<td>Washington Health Plan Finder</td>
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</tbody>
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<table>
<thead>
<tr>
<th>ENROLLMENT INTO DDA</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>DDA Application and Eligibility*</td>
<td></td>
</tr>
<tr>
<td>DDA Eligibility and Service Guide</td>
<td></td>
</tr>
<tr>
<td>How to Apply for DDA Services in Washington State</td>
<td></td>
</tr>
<tr>
<td>DDA Eligibility and Service and Information Request</td>
<td></td>
</tr>
<tr>
<td>Early Childhood Transitions and DDA Role ESIT Services</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FINANCIAL SERVICES</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ben's Fund</td>
<td></td>
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<tr>
<td>UHCCF Medical Grant</td>
<td></td>
</tr>
<tr>
<td>Prescription Assistance-NeedyMeds</td>
<td></td>
</tr>
<tr>
<td>Washington Autism Alliance Grants</td>
<td></td>
</tr>
<tr>
<td>Medicare Reimbursement Program</td>
<td></td>
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<tr>
<td>Apple Health Premium Program</td>
<td></td>
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<tr>
<td>Seattle Children's Financial Assistance</td>
<td></td>
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<tr>
<td>Sacred Heart Hospital Patient Financial Assistance</td>
<td></td>
</tr>
<tr>
<td>MultiCare Financial Assistance</td>
<td></td>
</tr>
<tr>
<td>Social Security Income Application</td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>NeedyMeds has a comprehensive list of grants by diagnosis and state in addition to prescription assistance</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>NUTRITION SUPPORT</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>CYSHCN Nutrition Network</td>
<td></td>
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<tr>
<td>Feeding Teams</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>FOOD, HOUSING, TRANSPORTATION SECURITY</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>WIC Nutrition</td>
<td></td>
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<tr>
<td>SNAP-Washington Connection</td>
<td></td>
</tr>
<tr>
<td>Food Banks</td>
<td></td>
</tr>
</tbody>
</table>
| ADVOCACY, LEGAL, JUDICIAL SUPPORT | Housing and Essential Needs (HEN)-WA Connect  
Independent Living  
Roads to Community Living  
Independent Living Skills Program  
Non-Emergency Transportation  
|---|---|
| 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  
|---|---|
| TRANSITIONS ACROSS CARE | School to Adulthood Transition Planning  
Transition Triangle  
Healthcare Transition  
Age Transitions-Informing Families  
|---|---|
**CYSHCN Life course Transitions and Eligibilities**

CYSHCN come in and out of contact with many systems of care at different times in their life. 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.

The following guide, identified in 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. 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 various age points of 4,10, 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**

<table>
<thead>
<tr>
<th>AREAS OF TRANSITION</th>
<th>RESOURCES</th>
<th>GUIDANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DDA APPLICATION AND ELIGIBILITY</strong></td>
<td>DDA Eligibility and Service Guide Applying for DDA Services in WA DDA Eligibility Early Childhood Transitions DDA Eligibility Video (PAVE)</td>
<td>CYSHCN who have DDA services lose that access through an expiration on their 4th birthday. They need to reapply for eligibility to continue past four. The same is true for CYSHCN have DDA eligibility prior to age 10. CYSHCN lose eligibility on their 10th birthday through an expiration if they were determined eligible prior to age 10 under a developmental delay diagnosis. They will need to reapply for eligibility past age 10. CYSHCN who are DDA eligible prior to age 19 will need to have a review for continued eligibility if their last determination was before age 16. A review for continued eligibility is necessary on a CYSHCN client’s 20ths birthday if their eligibility determination was based on academic delays in Broad Reading and Broad Mathematics 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).</td>
</tr>
<tr>
<td><strong>CHILDREN’S INTENSIVE IN-HOME BEHAVIORAL SUPPORT (CIIBS) WAIVER, INDIVIDUAL AND FAMILY (IFS) SERVICES WAIVER, OTHER DDA WAIVERS</strong></td>
<td>CIIBS FAQ DDA Eligibility and Service Guide CIIBS Waiver IFS Waiver</td>
<td>There are 5 DDA waivers (Individual and Family Services, CIIBS, Basic Plus, Core and Community Protection). DDA Waivers provide access to Medicaid which can be very helpful for families with private insurance who experience financial barriers.</td>
</tr>
</tbody>
</table>
**APPLY FOR SOCIAL SECURITY INCOME (SSI)**

<table>
<thead>
<tr>
<th>SSI Fact Sheet</th>
<th>Child Disability Report for SSI</th>
<th>Social Security Help</th>
</tr>
</thead>
</table>

**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 |

**Medical transition planning** to adult PCP care should begin at age **16-17**

**Implementation** of Medical transition plan should occur at age **18+**
### Pediatric to Adult Transition Resource and Guidance

<table>
<thead>
<tr>
<th>SCREENINGS</th>
<th>Bright Futures Pediatric Screenings by Age</th>
<th>Screenings recommended at various ages throughout the life course. Refer to Bright Futures Guide.</th>
</tr>
</thead>
<tbody>
<tr>
<td>APPLY FOR APPLE HEALTH</td>
<td>Applying for Apple Health Washington Health Plan Finder</td>
<td>Ensure your client has applied for Apple Health at any age throughout their life course.</td>
</tr>
<tr>
<td>MEDICAL DIAPERS 3+</td>
<td>Medical Diaper Authorization</td>
<td>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</td>
</tr>
<tr>
<td>EARLY HEAD START</td>
<td>Early Head Start</td>
<td>See the Early Head Start description in the Systems of Care section</td>
</tr>
<tr>
<td>HEAD START</td>
<td>ECEAP and Head Start Head Start</td>
<td>See the Head Start Description in the Systems of Care section</td>
</tr>
<tr>
<td>EARLY SUPPORT FOR INFANTS AND TODDLERS (ESIT)</td>
<td>Early Intervention Services ESIT Transition</td>
<td>See ESIT description in the Systems of Care section. <strong>IMPORTANT:</strong> 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</td>
</tr>
<tr>
<td>FIRST STEPS</td>
<td>Infant Case Management First Steps and Infant Case Management Provider Directory</td>
<td>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 birthday.</td>
</tr>
<tr>
<td>SPECIAL EDUCATION</td>
<td>Special Education Overview Early Childhood SE Secondary Transition</td>
<td>See Local School District description in the Systems of Care Section See Childcare/Education description in the Systems of Care Section</td>
</tr>
</tbody>
</table>
**Transition Planning Resources**

**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**

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**
- **Transition Planning Toolkit (Highschool, work, life, PAVE)**
- **HCA Workers with Disabilities**

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 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 determined 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 to 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 factors 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 managed care plans offer varying rates that are not disclosed publicly. Managed Care Plans will disclose their rates to participating
agencies in private meetings. The following is a publicly disclosed document with suggested the range of reimbursement rates. Reimbursement Rates

Managed Care Organizations (MCO): When participating with the Health Home program, each participating agency will need to partner with at least one Managed Care Plan. It will be important to consider which manage care plans 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.

MCO Associated 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.
- *Can acknowledge at the beginning of documents of both and speak to which is chosen for the document but validate both perspectives
- Shying away from acknowledgement can reinforce idea of disability as something of shame
  - **Note**: The word special is a 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.

<table>
<thead>
<tr>
<th>Avoid</th>
<th>Alternative</th>
</tr>
</thead>
<tbody>
<tr>
<td>crazy, mad, psycho, lame</td>
<td>person with mental health condition/illness*</td>
</tr>
<tr>
<td>defect, disorder, disease, illness</td>
<td>person with a congenital disability, person living with congenital disability, condition, diagnosis (neutral language)</td>
</tr>
<tr>
<td>normal, healthy, able-bodied</td>
<td>non-disabled</td>
</tr>
<tr>
<td>condescending language like differently-abled, challenged, handi-capable, etc.</td>
<td>Person with a disability</td>
</tr>
<tr>
<td>Handicapped</td>
<td>“person with a disability” or “disabled person”</td>
</tr>
<tr>
<td>*Special Needs</td>
<td>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</td>
</tr>
<tr>
<td>High Functioning/Low Functioning</td>
<td>*Significantly impacted, still considering as a team</td>
</tr>
<tr>
<td>Nonverbal</td>
<td>*Does not communicate using oral communication. Use non-speaking.</td>
</tr>
<tr>
<td>Suffers from/victim of/stricken with</td>
<td>“they have/are living with muscular dystrophy” is preferred to “they suffer from muscular dystrophy.”</td>
</tr>
<tr>
<td>Wheelchair-bound</td>
<td>Use “wheelchair user” or “person who uses a wheelchair.”</td>
</tr>
</tbody>
</table>
Mental Retardation | Use “person with an intellectual disability.”

<table>
<thead>
<tr>
<th><strong>Rethinking &quot;Vulnerable&quot; and Related Terms</strong></th>
<th><strong>Suggested Alternatives</strong> (alphabetical order only)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>At-risk</strong></td>
<td>Groups who experience a disproportionate burden of [poor health]</td>
</tr>
<tr>
<td><strong>Disadvantaged</strong></td>
<td>Groups who experience health inequities</td>
</tr>
<tr>
<td><strong>Disenfranchised</strong></td>
<td>Participants in life stages that may give rise to vulnerability</td>
</tr>
<tr>
<td><strong>Marginalized</strong></td>
<td>People we oppress through policy choices and discourses of racial inferiority</td>
</tr>
<tr>
<td><strong>Susceptible</strong></td>
<td>Priority population</td>
</tr>
<tr>
<td><strong>Underserved</strong></td>
<td>Structural vulnerability / Structurally vulnerable</td>
</tr>
<tr>
<td><strong>Vulnerable</strong></td>
<td>Name the source(s) of vulnerability: bias, cis-hetero domination, discrimination, health inequity, misogyny, oppression, policy, racism, segregation, white supremacy, etc</td>
</tr>
</tbody>
</table>

When Discussing Equity

When referencing disparities, emphasize valuing of equal opportunity for health that reducing disparities contributes to.

Consider:

- Systemic and social inequities-increased risk of illness
- **Avoid implying responsibility** for increased risk of adverse outcomes
- Use 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.
<table>
<thead>
<tr>
<th>Avoid</th>
<th>Alternative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underserved people; the underserved; hard to reach; the <strong>uninsured</strong></td>
<td>People who are underserved; people who are medically underserved; people without health insurance; <strong>underrepresented</strong></td>
</tr>
<tr>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>Homeless people; the homeless; transient population</td>
<td>People experiencing homelessness; persons experiencing unstable housing/housing insecurity; persons who are not securely housed</td>
</tr>
<tr>
<td>Poverty-stricken; the poor; poor people</td>
<td>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)</td>
</tr>
<tr>
<td>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).</td>
<td></td>
</tr>
<tr>
<td>High-risk people; high-risk population; vulnerable population; priority populations</td>
<td>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]</td>
</tr>
<tr>
<td>Pregnant women; mothers-to-be; expectant mothers</td>
<td>Use terms that are inclusive of all gender identities: Pregnant people; parents-to-be; expectant parents</td>
</tr>
<tr>
<td>Rural</td>
<td>People who live in rural/frontier areas; residents/populations of rural areas; rural communities</td>
</tr>
<tr>
<td>Referring to people as their race/ethnicity (e.g., Blacks, Hispanics, Latinos, Whites, etc.)</td>
<td>Preferred terms for specific racial/ethnic groups:</td>
</tr>
<tr>
<td>• Indian (to refer to American Indian); Eskimo; Oriental; Afro-American; Negro; Caucasian</td>
<td>• 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</td>
</tr>
<tr>
<td>• the [racial/ethnic] community (e.g., the Black community)</td>
<td>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.</td>
</tr>
<tr>
<td>• non-White (used with or without specifying non-Hispanic)</td>
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</tr>
</tbody>
</table>

WASHINGTON STATE DEPARTMENT OF HEALTH
CYSHCN PROGRAM

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| 46 |  |
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.\textsuperscript{22, 23}

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 (approx. 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

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. CYSHCN 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 HCAMCP@hca.wa.gov.

2. 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.

3. You can reach out to the MCO CYSHCN coordinators in the CYSHCN Coordinator Contact list
## MCO Point of Contact Information

<table>
<thead>
<tr>
<th>General Contact Information</th>
<th>Referral Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amerigroup</td>
<td><a href="mailto:cmrefwash@amerigroup.com">cmrefwash@amerigroup.com</a></td>
</tr>
<tr>
<td>Coordinated Care of Washington</td>
<td><a href="mailto:CareManagement@coordinatecarehealth.com">CareManagement@coordinatecarehealth.com</a></td>
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<td><a href="mailto:CareMgmtReferrals@chpw.org">CareMgmtReferrals@chpw.org</a></td>
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<td><a href="mailto:wa_carecoordinationrequests@uhc.com">wa_carecoordinationrequests@uhc.com</a></td>
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<td>Cassie Mitson</td>
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<tr>
<td>UnitedHealthcare</td>
<td>Amy Herdman</td>
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</table>

**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’s 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 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.
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
- Amerigroup 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

Map of NDCs and MFRBs

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

Maxillofacial Review Boards (MFRBs)
- Public Health - Seattle and King County
- Multicare Mary Bridge Tacoma
- Providence Sacred Heart
- Yakima Valley Memorial Hospital, Children’s Village
- Shared by Providence Sacred Heart and YVMH
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
References

22. Beth Clark NP. Exploring the Concept of Vulnerability in Health Care. 2018;190(11).

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