



Children & Youth with Special Health Care Needs

www.doh.wa.gov/cyshcn

COMMUNICATION NETWORK MEETING

April 13, 2023

CYSHCN Communication Network Purpose:

Provide for exchange of information among those programs and entities that serve children with special health care needs and their families and facilitate an opportunity to learn more about statewide policies, programs and issues critical to this unique population.

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Attendees

Attendee	Phone	Email Address
Amanda McCleskey, DSHS, ALTA Fostering Well-Being Care Coordination Unit	360-725-2503	McCleAL@dshs.wa.gov
Anna Cruz		Anna.Cruz@clark.wa.gov
Autumn Wade, DSHS, ALTA Fostering Well-Being Program	360-725-3541	WadeA@dshs.wa.gov
Becky Van Pelt, Benton Franklin Health District	509-460-4248	beckyv@bfhd.wa.gov
Bella Mendez, DOH, Child Health	(564) 669-3183	bella.mendez@doh.wa.gov
Bonnie Peterson, Thurston Co Public Health & Human Services	(564) 669-3183	bonnie.peterson@co.thurston.wa.us
Cari Hammond, Chelan-Douglas Health District	(509) 886-6400 Ext. 411	cari.hammond@cdhd.wa.gov
Cassie, UHC	509-574-3260	cathybuchanan@yvmh.org
Charla Morrow, Amerigroup Washington Medicaid		Charla.Morrow@anthem.com
Chris Gray, WithinReach	206-830-7641	christineg@withinreachwa.gov
Christin Seo, Snohomish Health District		Christin.Seo@co.snohomish.wa.us
Colleen Bradley, PAVE		cbradley@wapave.org
Crisha Warnstaff, Okanogan County, Public Health Nurse		lwarnstaff@co.okanogan.wa.us
Debbie Hamm, Adams Co Health Department		debbieh@co.adams.wa.us
Dennis Trudeau, DDA		dennis.trudeau@dshs.wa.gov
Derek Steele, Amerigroup		derek.steele@anthem.com
Diana Castillo		
Elizabeth Custis, RN, Mason County Public Health, CSHCN	360-427-9670 x 407	elizac@co.mason.wa.us
Elizabeth Stringer, Garfield County Health District		Estringer@co.garfield.wa.us
Estasia Collins, Columbia County Public Health Nurse	509-382-2181	estasia_collins@co.columbia.wa.us
Faire Holliday, DOH		Faire.Holliday@doh.wa.gov
Gabriela Ewing, Hispanic Disability Support, SWWA		info@pasitosgigantes.org
Gayle Reid, Cowlitz Co Health Department	360-414-5599 ext 6424	reidg@co.cowlitz.wa.us
Heather Gallagher, Arcora Foundation		hgallagher@arcorafoundation.org
Iana Bezman, HCA		iana.bezman@hca.wa.gov
Jan Schmalenberger, Clark County, CYSHCN		Jan.Schmalenberger@clark.wa.gov
Janet Vaupel, Walla Walla		jvaupel@co.walla-walla.wa.us
Janet Wyatt, Kitsap Public Health District		janet.wyatt@kitsappublichealth.org
Jason Akins, DSHS DDA		jason.akers@dshs.wa.gov
Jasper Brezsny-Feldman		

Attendee	Phone	Email Address
Jennifer Sass-Walton, Skagit County Public Health	360-416-1529	jennis@co.skagit.wa.us
Jesenia Stark, FWB		jesenia.stark@dshs.wa.gov
Jessalynn Jones, Cleft Lip & Palate	509-574-3260	JessalynnJones@yvmh.org
Jessica Hazen		JessicaHazen@seamarchc.org
Jessica Nye, SJC, HCS		jessican@sanjuanico.com
Jodi VanVleet, SLP, Children's Therapy Center, Neurodevelopmental Centers' Representative	253-216-0845	jodi@ctckids.org
Jolene Erickson RN BSN PHN, Lincoln County Health Department	509-215-1025	jerickson@co.lincoln.wa.us
Jordan Tracy, Tacoma-Pierce County Health Department	253-649-1912	jtracy@tpchd.org
Julia Kintz		julia.kintz@esd112.org
Kate Orville, Medical Home Partnerships for CYSHCN , UW Center on Human Development and Disability	206-685-1279	orville@uw.edu
Kelly Anderson, Molina Healthcare		Kelly.Anderson@molinahealthcare.com
Kelly Temby-Sturtevant	360-397-8000 x7400	kelly.blanchard@clark.wa.gov
Khimberly Schoenacker, DOH CYSHCN Nutrition Consultant	360-236-3573	Khimberly.Schoenacker@doh.wa.gov
Kindra Ahman, Tacoma-Pierce County Health Department		KAhmann@tpchd.org
Kristen Moberg, Molina		Kristen.Moberg@molinahealthcare.com
Kristin Lester, RN, Spokane Regional Health District		klester@srhd.org
Kristina Smith		kristina@kindredjoycoaching.com
Kristol Parker, Community Health Plan of Washington	206-408-4742	Kristol.Parker@chpw.org
Kristy Scheidt, Joya Child & Family Development		kristina@kindredjoycoaching.com
Kyser Corcoran, DSHS FWB		kristina@kindredjoycoaching.com
Lauren Spilles		
Leah Bretland, Snohomish Health District		leah.bretland@co.snohomish.wa.us
Linda McCaulley, Skamania County Community Health		mccaulley@co.skamania.wa.us
Linda Porter		porterlinda@hotmail.com
Linda Ramirez, DOH CYSHCN Communications & Early Child Health Consultant		linda.ramirez@doh.wa.gov
Lisa Ross, DSHS DDA	509-329-2881	Lisa.ross@dshs.wa.gov
Lora Gittins, Asotin Co Health District	509-552-4122	lgittins@ac-hd.org
Loretta Bezold, Island County Health Department	360-678-8281	l.bezold@islandcountywa.gov
Luke Trembley, RD, Clark County WIC Coordinator		luketrembley@seamarchc.org
Lupita Espinoza, CDHD		lupita.espinoza@cdhd.wa.gov
Malvina "Annie" Goodwin, Benton-Franklin Health District	509.460.4246	Annieg@bfhd.wa.gov
Mandy Herreid, UHC	(763) 361-1470	mandy_herreid@uhc.com

Attendee	Phone	Email Address
Mari Mazon, University of Washington, Nutrition Program	206-598-3025	lilmaro@uw.edu
MarSue Chagnon, RN		marthasue.chagnon@providence.org
Mary Jo Schatz, Tacoma-Pierce County Health Department	253-649-1912	mschatz@tpchd.org
Melissa Petit, HCA		melissa.petit@hca.wa.gov
Molly Corvine, NECHD		mcorvino@netchd.org
Monica Burke, DOH CYSHCN Director	360-236-3504	monica.burke@doh.wa.gov
Natalie Todd		ntodd@netchd.org
Nathalyn Dagdagan, DSHS DDS NCC		nathalyn.dagdagan@dshs.wa.gov
Nichelle Brown		nichelle.brown@ctckids.org
Nicole Christiansen, Klickitat County HD	509-773-2367	nicolec@klickitatcounty.org
Nikki Dyer, DOH/Children and Youth with Special Health Care Needs	360-236-3536	nikki.dyer@doh.wa.gov
Patricia Squires, DSHS DDA		patricia.squires@dshs.wa.gov
Renee Tinder, Behavioral and Adolescent Health Consultant DOH		Renee.Tinder@doh.wa.gov
Sara Brugger, Clark Co Public Health		sara.brugger@clark.wa.gov
Sarah Bunney, Joya Child & Family Development		sarah.bunney@joya.org
Sarah Harsh, UW CHDD		sbharsh@uw.edu
Sharon Bennatts, RN Coordinated Care	253-442-1543	sbennatts@coordinatedcarehealth.com
Shawnda Hicks, PAVE		shicks@wapave.org
Stacey Wyatt		stacey.wyatt@elevancehealth.com
Sue Adelman, UW LEND		adelms@uw.edu
Suzie Tallar, Coordinated Care	253-442-1527	Suzanne.E.Tallar@coordinatedcarehealth.com
Sydney Doherty, Coordinated Care		Sydney.L.Doherty@coordinatedcarehealth.com
Tracie Hoppis, Children's Village/P2P	509-574-3263	traciehoppis@yvmh.org
Trishia Benshoof, DCYF		trishia.benshoof@dcyf.wa.gov
Whitney Wheelock, Kittitas County Public Health		whitney.wheelock@co.kittitas.wa.us

Guests:	
Daniel M. Walsh, DMD, MSD	walsh2013@alumni.ohsu.edu
Angella Southerly, Light A Lamp	asoutherly@lightalamp.org
Aarika D. Anderson Elter, DMD, Special Olympics WA	aarikaanderson@gmail.com
Sarah Harsh, MS, RDN	sbharsh@uw.edu

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

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

Staff Updates

CYSHCN Process Improvement Specialist Position is posted and closes 4/18

HRSA Region 10 (WA, OR, ID, AK) [Conversation on Equity: Language Access—More Than Just Translation](#)

CYSHCN Team has provided trainings on [Care Coordination Toolkit](#) to NDCs and MCOs and is working on a revision of the toolkit based on feedback received.

CHIF

CHIF data for Q4 for all partners due 4/15. If anyone needs an extension or help, please contact the CHIF Inbox.

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

Please direct any questions about CHIF to the CHIF Inbox.

CHIF dashboard to be published soon with 2011-2021 data included for all counties, LHJs, ACHs, and all state roll-up.

Planning for improved CHIF system is ongoing and we will be reaching out to partners over the next few months to engage in the redesign process

Family Engagement

Recruiting for diverse [Family Advisory Council](#) to guide care coordination work done in partnership with HCA and PAVE.

Leading DOH internal Community of Practice on using Family Voices' Family Engagement in Systems Assessment Tool (FESAT) to measure and guide improvement on family engagement efforts within CYSHCN and in partner units.

Supporting kick-off of Gen 2 Youth Advisory Council in collaboration with Adolescent Health team.

For more WSLI or DOH Family Engagement information, contact Nikki Dyer at 360-236-3536 or nikki.dyer@doh.wa.gov.

Behavioral and Adolescent Health

Pediatric Mental Health Care Access expansion fund projects with Seattle Children's Emergency Department and the UW Medical Homes Project are underway. Participating in a technical assistance collaborative with other PMHCA grantees who are focusing on expanding ED services/suicide prevention. Provider survey went out to SMART teams and community coordinators across the state, and we received over 80 responses that will inform our plan for training.

Nearly ready to kick off year 2 PMHCA-SAFES program services in partnership with SCH and Frontier Behavioral Health

*For more Behavioral and Adolescent Health information, contact Renee Tinder at 360-584-7665
Renee.Tinder@doh.wa.gov.*

CYSHCN Program Nutrition Updates

The Type 1 Diabetes (T1D) workgroup continues to hold monthly meetings with recent focus on mental health, teen virtual support and rolling out the new T1D Statewide Coordinator role.

CYSHCN-WIC Office hours continue to be available for CYSHCN Nutrition support monthly with a topic discussed.

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

CYSHCN Communication & Early Childhood

Working with Child Health and Essentials for Childhood team on communication plan.

CYSHCN is working to redesign/update DOH CYSHCN website.

CYSHCN Brochure: New translation added ([Marshallese](#))

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

Essentials for Childhood (EFC)

For more information, contact Bella Mendez at www.doh.wa.gov/efc.

Universal Developmental Screening (UDS)

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

MCH LHJ Contracts Updates

No Updates at this time

For more information, please contact Kara Seaman at Kara.seaman@doh.wa.gov.

Guest Presentations

Dental Care for Children/Youth with Special Healthcare Needs

Daniel Walsh, DMD MSD

Introduction:

- Associate Pediatric Dentist at Small to Tall Pediatric Dentistry in Olympic, WA
- Attended Saint Martin's University for undergrad.
- Oregon Health & Science University for Dental School
- Idaho State University for Advanced Education in General Dentistry Residency where he provided care in a hospital setting to adults with special healthcare needs, as well as advanced dental care such as surgery and also treated children with complex dental needs regularly
- Continue with private practice in the South Puget Sound area as a general dentist, taught at the local dental assisting program, and volunteered providing emergency dental surgery at the Union Gospel Mission
- Attended Pediatric Dental Residency at the Seattle Children's Hospital and University of Washington program and now work in private practice in Olympia, WA with Small to Tall Pediatric Dentistry
- Dr. Walsh has been treating patients for 14 years.
- In addition to direct patient care, Dr. Walsh also has a strong interest in research and just received confirmation that his manuscript from research that he conducted at Seattle Children's Hospital will be published next month.

Our Patients:

- Small to Tall Pediatric Dentistry sees a broad age range of patients from ages 4 months to 22+ years old.
- Small to Tall Pediatric Dentistry specializes in the care of children with special healthcare needs.
- For example:
 - Children who are in recovery from cancer after they are in remission
 - Children who received a transplant and are stable for 6+ months can be seen in a community setting

- As long as a child is not physically violent or unsafe to the dental, we accommodate the care of behaviorally complex children.
- We perform routine treatment for children with well controlled bleeding disorders, seizure disorders, respiratory issues, cardiac disease, and debilitating progressive medical conditions.
- Small to Tall Pediatric Dentistry form close partnerships with members of the medical community as well as physicians and pediatric dentists at Seattle Children’s Hospital to ensure optimal care for these children and families.

The Dental Home:

- A child should establish with a dental home early. As soon as a child has their first tooth, it is recommended that they begin seeing a dentist.
- ABCD: Providers who participate in the ABCD program can receive enhanced reimbursement for children five and under with Medicaid insurance. Unfortunately, pediatric dentists do not routinely accept Medicaid. It has been documented that children with special healthcare needs have lower rates of unmet dental needs and better access to care in areas with higher Medicaid reimbursement. Recently, the ABCD program was expanded to include children with special healthcare needs ages 6-13.
- Office design can play a very big role in a patient’s experience. While dental offices are required to be accessible to patients under ADA guidelines, they do not always comfortably accommodate children with special healthcare needs.
- As pediatric dentists, it is our goal to make visits as accommodating as possible and many of our offices are designed to be more comfortable for children.

Communication:

- As pediatric dental providers, we focus on using person-first language. That is, recognize children as a person before their medical condition.
- Examples:
 - “Child with a diagnosis of autism spectrum disorder” vs “autistic child”
 - “Child with a diagnosis of trisomy 21/Down syndrome” vs “Downs child”
 - “The child uses a wheelchair” vs “wheelchair-bound child.”
- Ableism → avoid: pity, awe and inspiration, denial and minimalization, assumptions and generalizations, infantilization

Dental Visits:

- Dental visits should be customized to every child
 - A new patient visit will generally be up to an hour but return visits should be kept as short as possible. There will be extensive discussions about a child’s medical and dental history. Sometimes these examinations are due to a referral from another dental provider due to the presence of a specific dental condition, other times they are just to establish care.
 - When possible, the dental team member will introduce the dental operator, instruments, and discuss a plan with the child.
 - After these steps, which may include a dental cleaning or dental X-rays, the dentist will come into the room and greet the family. For example, always say hi to the child and address them directly, regardless of their ability to communicate or perceived level of awareness. It is important to avoid assuming someone’s communication abilities may be lacking based on their outward appearance.
 - Have as much discussion in the beginning as possible depending on what information is available. As best as possible, try to keep language kid friendly and avoid the family or child having to relive negative past medical or dental experiences. This conversation time during the visit allows the child to play or watch and settle in and adjust to a new person being in the room. As a provider, also try to determine what triggers a child may have, as well as what types of reward system they respond to.

Sometimes a child will also participate and answer questions themselves, when able. Always make an effort to identify the child or family's chief concern- the reason they are seeking dental care, as well clarify a family's expectations for the visit.

- The chief concern should be addressed first. This is why the child and family came in and has likely been at the forefront of their mind for quite some time. From there, we will have specific conversations about nutrition, oral care, prevention, growth and development, and any treatment recommendations.
- The key take-home point for success during a dental visit is to trust the parents: they know the child and many times can provide valuable information about the child to help the dental team with a successful visit.

CYSHCN: Oral Hygiene and Nutrition:

- Children with special healthcare needs tend to have a higher incidence of poor oral hygiene, gingivitis, and more untreated dental decay.
- These children receive more extractions than repairs and receive less preventive care.
- We find that children with special healthcare needs have nutritional demands, eating habits, and food preferences that are different from other children and place them at greater risk for the development of dental decay.
- Nutritional challenges:
 - Decreased ability to consume nutritious food (oral motor dysfunction)
 - Inability to utilize calories (GERD)
 - Increased caloric requirement (hyperthyroidism)
 - Medications may affect appetite (ADHD)
 - Condition may increase appetite (Prader Willi Syndrome)
 - Patient may have a selective or limited diet (autism spectrum disorder)
 - Oral medications may come in sweetened liquid suspension
- As pediatric dentists, we sometimes discuss feeding modifications and preventive measures for families to consider:
 - Using rewards that are less cariogenic. For example, rather than giving a gummy or fish crackers as positive reinforcement, finding a healthier reward (such as tokens, prizes, fruit, or even a chocolate chip would be better)
 - Children at higher risk for dental caries should have increased cleanings at home
 - For children with sensitivities, mildly flavored or flavorless toothpaste is available
 - Where appropriate, pediatric dentists should communicate with the medical team to discuss ways to reduce a child's caries risk

Common Findings:

- Common findings among children with special healthcare needs include:
 - Bruxism or tooth grinding: I see this commonly in children with sensory differences, as well as children who use a feeding tube for nutrition. It comes up as one of the top chief concerns brought up by parents.
 - Tartar or hard deposit buildup: Another top concern mentioned by parents- this is common when oral hygiene at home is difficult as well as for children who do not eat by mouth.
 - Gingival overgrowth is common, particularly in patients who take certain seizure medications.
 - Dry mouth is another common finding. Medications taken by children with asthma, ADHD, ASD, cerebral palsy, with congenital heart disease, gastric reflux, and seizure disorders can all cause this common oral finding that contributes to an increased risk for dental decay.
 - Oral candidiasis is common due to poor oral hygiene and/or immune impairment
 - Overproduction of saliva frequently occurs in children with a diagnosis of cerebral palsy

- In addition to complex health challenges encountered by children with various genetic syndromes, we commonly see oral findings of extra or missing teeth, TMJ disorders, enamel defects, and craniofacial developmental anomalies.

Autism Spectrum Disorder:

- 1 in 36 US Children is diagnosed with Autism.
- Restrictive, repetitive interests/behaviors may be quite common. These children may have a significant preference in routine, lack pro-social communication, and have interests that are unusual and intense. Motor mannerisms are also common such as hand flapping, finger flipping, twisting, rocking, swaying, dipping, and toe walking.
- Some of these children may have restrictive food preferences, unique eating routines, and may avoid certain textures.
- Children may have repetitive speech patterns and questions.
- At times, I commonly see that children with a diagnosis of autism have very rigid expectations and deviations from routine can be difficult.

Autism Spectrum Disorder: The Dental Visit

- Ways that dental providers can promote success for these children in the dental environment include:
 - Being supportive of children who utilize social stories. This can be done by either posting pictures or videos describing the dental visit at your office or allowing families to take photos during the visit. I routinely describe my entire plan to a child and/or narrate the visit in an effort to help a child prepare for next steps.
 - Keeping the same provider team and room and establishing a reliable routine for the visit is a must
 - When interacting with a child, the dental team and parents must have realistic expectations for the visit. When working with a child as a new patient, we must recognize that it could be years before a child can come in, lay in the dental chair, take X-rays, have a cleaning, and have a full examination.
 - The dental team and family should focus on exposing children to new things at every visit. I work to partner with families and have them recognize that I embrace doing things that we know the child is close to mastering while also having parts of the visit that are new and challenging. It's ok if we don't have a perfect visit. Overcoming challenges is part of building new skills and parents/families should be reassured that the provider team is patient and committed to helping their child make gains.
 - Counting is very helpful for children needing more reassurance. For the most hesitant children, I will slowly count on their parent's hand with my dental mirror, then on the child's hand, then I will touch the parent's face, then the child's face while counting. This back and forth with their parent modeling the experience coupled with counting has been VERY successful for me. Sending a dental mirror home and having a child's guardians practice this at home can improve future dental visits and help ease a child into allowing for better oral care at home.
 - Sometimes the dental chair is very scary to children- for older children I am comfortable doing examinations with them sitting up, but I've been known to get down on my knees on the floor while a child is standing, and I've even done full examinations while a child repeatedly yawned. We meet the kids where they are!
 - Depending on the child's sensory profile, celebrating every achievement and helping with positive reinforcement is key.
 - It's important to note that some patients may be unable to have a traditional dental examination and, when urgent or when a child does not demonstrate cooperation in other aspects of their life, there are times when an examination must be completed even when a child is unwilling, in order to

determine if a more thorough examination and treatment under general anesthesia may be indicated.

Sensory Adapted Environment:

- Some providers utilize sensory adapted environments for introducing the dental experience.
 - Being able to put on low lighting, relaxing music, utilize a TV above the chair with headphones, and having comfortable chairs like bean bags may be helpful.
 - At UW and now in private practice

Social Determinants of Health:

- There are so many factors to consider when treating children with special healthcare needs. As pediatric dentists, we need to look beyond only treating oral conditions.
 - We spend time looking at the complex health issues faced by a child.
 - We see many children from a complex social situation and work to bridge gaps in care.
 - And we have a responsibility to improve access to care for children and families.
- How does my office currently do this?
 - We engage physicians in the community and routinely consult with care providers.
 - We work with social workers and other clinics in the region to help connect children with services.
 - We participate in the ABCD program, have no age restrictions for children with special healthcare needs who have Medicaid insurance, and we accept referrals for treatment by other dental providers and physicians for patients who have Apple Health
- Every child we meet has a large team supporting them and pediatric dentists can also serve as a member of this team.
- In my training, I did rotations with developmental pediatricians, ABA therapists, speech therapists, and worked closely with social workers.
- Many pediatric dentists should have familiarity with the services you all provide, and I encourage you to engage them in your community.

Questions:

Q: What would you recommend for young children with severe tooth grinding?

A: Big concern that that is frequently brought up by parents. If there is no medical issue and children are just grinding their teeth, there's no intervention. If the grinding is severe intervention will be considered.

Q: Do you see children with cleft palate that are involved in the Maxillofacial board?

A: No

Q: What families are supposed to do with their young adults with special needs when there're no providers that provide full sedation? Do they need to go to the hospital to get care? How can they deal with their children/adults in pain all the time?

A: Recommended to go to providers in residency clinics.

You can look up your local ABCD coordinator at this site, they all have resource lists for children: <https://abcd-dental.org/local-abcd-programs/>

Freemectomy dentist list for Clark County:

- Adventure Dental
- Brester Dentistry
- Must Love Kids
- Shebani/Kim

A Mom's Perspective

Angella Southerly, Light A Lamp

2005 Brandon's Story Began...

- Brandon was born in 2005.
- Brandon was born with a soft cleft palate.
 - A lot of soft cleft palate aren't seen on ultrasounds.
- Children can be born with a cleft lip, or the cleft can be in the hard palate and the soft palate or just the soft palate. Or it can come through the nose and be unilateral or bilateral.
 - There are so many different levels of this condition.
 - This cause assumption and unawareness of the condition.
- Clefts cause eating difficulties and getting nutrition into the child.

Opportunities to prevent further medical issues:

- Brandon was the first of 12 babies to be born with a cleft in the Spokane area in the year of 2005.
- Angella notice that Brandon was having difficult time being feed.
- Various health workers have opportunities to look for soft cleft palates.
 - In Brandon's case this opportunity came when a nurse had the opportunity to notice, when they were bathing him, but did not notice it.
 - This could have prevented further medical issues in the future.
 - Bringing awareness to healthcare workers to look for issues like cleft palate.
 - Early detection will save lives and will definitely stop secondary health conditions.

Moms know if something is wrong...

- Nursing Staff should encourage new moms to express:
 - Feelings
 - Fears
 - Feedings
- Lactation consultants are important resources for mothers.
 - The lactation consultant was the first to notice Brandon sound different and asked if he was checked for soft cleft palate.

Back at the hospital 5 days old:

- Angella did not know what was wrong at the time and was feeding Brandon through syringe into his mouth, which also did not work.
- Angella brought Brandon to Pediatrician, where that pediatrician sat in listen to Angella concerns.
 - He examined Brandon and diagnosed him with a soft cleft palate.
 - Because of the lack of nutrition Brandon ran the risk of having brain damage and kidney failure at just five days old.
 - Brandon was sent to an oncologist and was admitted.
 - Brandon had jaundice, was very dehydrated, and weight loss.
 - Children with cleft aspirate really easy. .

Back at home again...

- Baby Brandon is now eating thanks to their Nurse Coordinator that supplied them with:
 - Knowledge
 - Specialty bottles, nipples, and valves.
 - Thickening agents and formula
 - Wedge and sling

Statistics:

- 1:650 births will have a cleft
- 1:500 births of Hispanic families are affected by cleft

Secondary Health Challenges:

- Learning
- Speech
- Mental Health

Success Story:

- Initial cleft repair at 11 months
- Pharyngeal flap at 3 years
- Still in need of a nasal surgery

How we support:

- Support in the Spokane area
- Provided support to families like gifting welcome baby baskets to families.
 - This is done confidentially.

Contact information:

- Angella Southerly
 - Light A Lamp
 - www.lightalamp.org
 - Facebook: @LightaLampnonprofit, @ProjectLiftUp, @Light a Lamp/Cleft Lip & Palate Partnership
 - Instagram: @lightalampnp

Questions:

Q: Do the current Maxillofacial Programs located at the hospitals/clinics provide home visiting by public health nurses?

A: Every Maxillofacial Programs have different routine.

Q: What happens to families not near the Maxillofacial programs?

A: There are different regions each Maxillofacial programs serve.

Info on the DOH funded Maxillofacial Review boards: <https://doh.wa.gov/sites/default/files/2023-03/350-039-MaxillofacialReviewBoardContactList.pdf?uid=6438397599e8b>

Special Olympics Special Smiles Program

Aarika D. Anderson Elter, DMD

Special Olympics is an Inclusion Movement:

- Founded in 1968 by Eunice Kennedy Shriver
- World's largest sports and health organization for people with Intellectual and Developmental Disabilities.
 - Special Olympics now reaches 6 million people worldwide
- BUT – we know there are an estimated 200 million people with ID in the world.

Healthy Athletes:

- In 1997, Special Olympics Healthy Athletes® began offering free health screenings and education to Special Olympics athletes in a welcoming, fun environment.

- Since then, we have delivered over 2 million free health screenings and trained over 300,000 health professionals and students to treat people with intellectual disabilities.
- Moreover, Special Olympics Programs have been able to expand their reach of Healthy Athletes, by offering over 120k screenings since 2016 in new locations or in new disciplines.
- In Washington, we offer health screenings in eight disciplines:
 - MedFest (history and physical exam)
 - Special Olympics Lions Clubs International Opening Eyes (vision/eye health)
 - Healthy Hearing (audiology)
 - Special Smiles (dentistry)
 - Health Promotion (prevention and nutrition)
 - Strong Minds (emotional health)
 - FUNfitness (physical therapy)
 - Fit Feet (podiatry)
- The impact of these screenings on the health and wellness of Special Olympics athletes around the world is significant. Healthy Athletes have discovered undetected health problems, alleviated pain and provided health services that otherwise would not be available.
- Healthy Athletes is not only a program for athletes but, through training and hands-on experience at screenings, it is a program for healthcare students and professionals to increase knowledge of best practices in caring for and communicating with people with intellectual disabilities.

What is Special Smiles?

- Special Smiles events are designed:
 - to increase access to dental care for Special Olympics athletes, as well as people with intellectual disabilities.
 - Raise dental professionals' awareness of the oral health concerns of people with special needs, including difficulties involved in accessing care.
 - Develop a body of knowledge about the oral health care needs of children and adults with disabilities.
 - Provide a list of regional dental professionals who care for people with special needs to all athletes who participate in Special Smiles.
- As a clinical director for the special smiles program, what keeps me involved year after year, is knowing that the Special Olympics partnership with CDC supports a range of health initiatives, including the development of the largest data set on people with IDD in the country—to better analyze the problem of health inequality and how best to address it.
- It is not possible to advocate for a problem, unless you can demonstrate that there is one. The Special Olympics Screening programs do just that- they collect the data to demonstrate the unmet healthcare needs of individuals with IDD.
- It has been well documented that dental care is the NUMBER ONE unmet health need in children with special healthcare needs and significant disparity still exists in oral healthcare between individuals with IDD and the general population
- [CDC and Special Olympics: Inclusive Health | CDC](#)

Unmet Healthcare Needs:

- Special Smiles examinations have found that a large percentage of Special Olympics athletes in the U.S. are unaware of the condition of their oral health.
 - 47% have gingival signs
 - 25% have untreated tooth decay
 - 9% received an urgent dental referral

- 12% have mouth pain
- Many Special Olympics Athletes do not have a dental home with providers who are trained to work with people with ID or that meets their insurance needs.

Barriers to Care for Patients with IDD:

- Lack of Trained Dental Providers
- Lack of Dental Benefits
- Lack of Accommodations
- [At NCD's recommendation, all U.S. dental schools will train students to manage treatment of people with intellectual, developmental disabilities | NCD.gov](#)

Volunteering for Special Smiles:

- Special Smiles screenings are supported by amazing volunteers including students, clinicians and general volunteers

Special Smiles Clinical Director Role:

- Clinical Directors are an important part of the Healthy Athletes Special Smiles team.
- Clinical Directors are responsible for working with Special Olympics Washington and other volunteer health professionals to coordinate Special Smiles screening events in their region.
- Clinical Directors will also support Special Olympics Washington to connect athletes with unmet healthcare needs to dental resources and providers in their community.
- We currently have 6 Clinical Directors in Washington supporting Special Smiles, but we are in the search of more dental providers in new areas of the state who are passionate about inclusivity and increasing access to healthcare!

Provider Referral Directory:

- Special Olympics Washington is developing a Referral Network of providers, organizations, and community-based services that are accessible and trained to serve people with ID.
- We provide these contacts to our athletes who receive a referral for further care after a Special Smiles screening.
- We encourage providers to take our introduction to intellectual disabilities e-learning module as a way to feel more comfortable and confident providing exceptional care for people with IDD.
- We need your help spreading the word to providers across the state, so all of our athletes have the opportunity to be treated by an accessible and trained dentist.

Questions:

Q: How could children/adults apply for dental services through Special Olympics when they're no part of your program? Do you have full sedation providers?

A: Special Olympics doesn't provide dental services to athletes, only provide screenings for only registered athletes.

Q: How could I request a Special Smiles Screening event in SW WA?

A: Contact the Special Olympics Washington Coordinator @ healthyathletes@sowa.org

Nutrition and Dental Concerns

Sarah Harsh, MS, RDN

Childhood Obesity and Dental Caries:

- Both are common childhood conditions.

- Several studies have found an association between the two.
- Both are complex conditions impacted by social determinants and individually modifiable factors.
- The dental office is a potential site for obesity screening and intervention.
 - The Robert Wood Johnson foundation Healthy Futures: Engaging the Oral Health Community in Childhood Obesity Prevention National Conference (2016) identified nutrition education through motivational interviewing as a potential model for intervention.

Nutrition and Feeding- Infants

- What are they eating?
 - Breastmilk
 - Formula
 - Complementary foods – pureed - table foods
- What's going on?
 - Weaning
 - Rapid growth and development
 - Development of parent-child interactions, relationship
 - Emotions around feeding
- Recommendations:
 - Feed on demand
 - Reinforce hunger/satiety cues
 - Establish trust
 - Practice drinking from a cup with water
 - no juice! And definitely not from a bottle or sippy cup
 - Start good habits early
 - Family meals
 - Food choices
 - Expose to a variety of flavors, both sweet and savory

First Foods:

- Watch for added sugar!
- Fewer ingredients usually means no (or less) added sugar- but there are sugar free convenience foods available!

Nutrition- Early Childhood:

- What are they eating?
 - Table food- modified to make it easier to eat
 - Small, frequent meals and snacks
- What's going on?
 - Growing sense of independence
 - Fine motor skill development
 - More interest in trying new foods along with struggles over foods
 - Unpredictable, impulsive
- Division of mealtime responsibility
 - A parent's job is to provide a variety of healthy foods
 - A child's job is to choose how much of those foods to eat
- Recommendations
 - Drink water when thirsty
 - Meals and snacks at regular, predictable times
 - Minimize grazing

- Gives children the privilege of coming to a meal hungry, but not too hungry

Nutrition and Feeding- Middle Childhood

- What's going on?
 - More social significance to food
 - Body image awareness
 - Identify as good as +/- healthy- but many not know why; typically does not affect choices
- What are they eating?
 - 3 meals, 1-3 snacks
 - Intake and with growth spurts
 - Less milk, fruits, vegetables
 - More sweetened beverages

Nutrition- Adolescence

- What are they eating?
 - Less milk, not enough fruits and vegetables
 - More sweetened beverages
 - More food away from home
- What's going on?
 - Develop identity
 - Foods have symbolic meaning, used to establish and express identity
 - Body image

What is the relationship between nutrition and oral health?

- Lower Rates of caries among children who scored highest on Healthy Eating Index (HEI)
 - Healthy Eating Index (HEI): Measures compliance with the diet-related recommendations of the DGA

CSHCN Coordinator Updates by County

Gathered from counties and shared on a quarterly basis.

Grays Harbor County Public Health

Erin Schreiber, Program Supervisor, Healthy Families Division

No updates at this time

Grant County Health District

Julia Austin, RN, BSN, Public Health Nurse

No Updates at this time

Island County Public Health

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

No updates at this time

Jefferson County Public Health

Apple Martine, Community Health Director

No updates at this time

Lincoln County Health Department

Jolene Erickson, Director

No updates at this time

Okanogan County Public Health District

Lacretia Warnstaff, Public Health Nurse

No updates at this time

Pacific County Children and Youth with Special Health Care Needs

Princess Klus, Care Coordinator-Family Navigator

No updates at this time

San Juan County

Kristen Rezabek, MS, RDN, CD, CDE, Health & Nutrition Coordinator

<https://www.sanjuanco.com/1777/Health-Community-Services>

Meeting monthly with our LatinX Advisory group. Held Community Asset Mapping meetings with community stakeholders in conjunction with Island County to develop a robust resource directory and update the Within Reach parenthelp123 Help Me Grow system of resources for our County. Launched a new public health wellness van nicknamed Luci B with plans to offer health screenings, immunizations, oral health and other community outreach and engagement events across the islands. UDS now implemented at 3 clinics in San Juan County. Meetings held with new Pediatrician in the county who is now COE trained and a provider serving on our San Juan County Autism Collaborative. Provided 4 new Autism diagnoses and working to connect families to support and services. Member of the newly formed Island/ San Juan Feeding Team in collaboration with STEPS (formerly Toddler Learning Center). Ongoing membership in the ECHO IDD and statewide SMART networking groups.

Spokane Regional Health District

Kristin Lester, RN

No updates at this time

Skagit Co Public Health Department

Jennifer Sass-Walton, Prevention & Community Health Manager

www.skagitcounty.net/health

We have been offering a child development CME series through our Help Me Grow Health Care Provider Action Team. These offers are free and open to anyone who is interested. Next Thursday's session is featuring Dr. Dimitri Christakis, speaking about the impact of technology on child development. Registration links, recordings and slide decks from past events are available at <https://helpmegrowskagit.com/healthcare-providers/>

We also partnered with the WA Chapter of AAP to support chronic disease management in school's collaboration with school nurses and local pediatric primary care providers. In January, the topic was ADHD management and how to get Vanderbilt assessments completed and sent to pediatricians. The April session was on insulin pumps and continuous blood glucose monitoring devices, presented by a nurse educator from Seattle Children's.

We are thinking about doing a Books, Blocks and Balls community child development event.

<https://helpmegrownational.org/wp-content/uploads/2018/06/Books-Balls-and-Blocks-Manual.pdf>

Thurston County Public Health and Social Services

Bonnie Peterson, RN, CYSHCN Coordinator

<https://www.thurstoncountywa.gov/departments/public-health-and-social-services/community-wellness/parent-and-child-cyshcn>

Most referrals are for children with ADHD, IDD, Autism with behavioral problems. Having difficulty finding behavioral therapists, Sensory therapy, nutritionists, and primary care providers. We have an increased need with a lack of providers. The majority of the therapists and providers only take a limited number of children on Medicaid. Long waits for neurodevelopmental and behavioral evaluations which leaves families frustrated and desperate to get interventions that can help. Started this year doing Work First evaluations for Lewis County in addition to Thurston. Completing an average of 10 Work First evaluations per month. Continue to provide consultation for interventions and resources for children with special needs to our NFP nurses and other health care providers in our community. Since we have had an increase in child abuse in the past 2 years, we have started focusing on increasing our training for home visitors to identify abuse, provide appropriate nursing interventions and support, and make referrals for needed support for the safety of the child.

Yakima County- Children's Village

Tracie Hoppis

<https://www.yakimamemorial.org/services/childrens-village/>

1. *Hosting monthly Yakima County Care Coordinator's meeting with presentations from local agencies serving CYSHCN and their families. This quarter had training with People for People (Medicaid transportation broker and Heartlinks Palliative Care.)*
2. *Moderated parent panel at Central Washington Transition (to adulthood) Symposium. Four parents shared their experiences with navigating transition to adulthood with their children.*
3. *Working with Parent to Parent at Children's Village as we bring back in-person support programming including support and sharing groups, family events, sibling support, and social/recreational programming. Parent to Parent offered 4 week Strengthening Families/Protective Factors training (in English and Spanish) to families.*

Neurodevelopmental Center (NDC) Updates

Joya Child & Family Development

Kristy Scheidt, Nurse Enrollment Coordinator & Lead FRC

www.Joya.org

Joya is reaching our first anniversary at our new location in the University district in Spokane, WA. We are excited to see steady growth in our program as we offer PT, OT, speech and teacher services along with a variety of toddler groups throughout the week. We work with outside providers to offer services from registered dietitians, TSVI and THOH. We have an urgent feeding clinic that provides prompt services for those little ones needing care quickly. We look forward to our Joya Community Day coming up in May. It's always a fun way to involve the community and our families past and present in our mission.

Mary Bridge Children's Hospital Therapy Services

Kari Tanta, Rehab Manager

<https://www.marybridge.org/>

Mary Bridge Children's Hospital Therapy Services is expanding! We welcomed our newest clinic in Renton this past fall when Children's Therapy of Valley Medical Center became part of Mary Bridge! We now offer outpatient therapy services in Renton, Puyallup, Tacoma, Gig Harbor, Lakewood, Federal Way and Olympia. Our team members also

provide pediatric therapy services at Tacoma General, Mary Bridge Hospital, Good Samaritan, and Valley Medical Center. We have expanded to also include a weekly Physical Medicine and Rehab Clinic at our Renton Location. Hiring continues at all of our locations to attempt to address the needs of families in all of our locations.

Children's Therapy Skagit Valley Hospital

Erin Kavi, Lead Therapist

www.skagitvalleyhospital.org

No updates at this time

Children's Therapy Valley Medical Center

Kari Tanta, Rehab Manager

www.valleymed.org

No updates at this time

Kinderling

Kathy Fortner Director of Operations

www.kinderling.org

No updates at this time

HOLLY RIDGE

Alicia Skelly, Infant Toddler Program Director

www.hollyridge.org

Holly Ridge continues to serve 380+ children per month. Holly Ridge is back to serving children in their homes and out in the community. We have several staff members that have completed CHERISH certification through Kinderling. Holly Ridge is now providing CHERISH services to children and families in the child welfare system.

SPARC

Amanda Sloan, SPARC Director

SPARC continues to grow in numbers. Referrals remain up. We recently hired a part-time Music Therapist and hoping to implement music therapy groups in partnership of our local Children's Museum within the next few weeks. This is a new service for SPARC, and we are wanting to implement it smoothly, so we have been taking our time creating smooth referral processes and communication with families. We are hoping to find grants to help cover the expense of this service as we are finding that most contract funds do not. If anyone learns of any, please let me know. We have also "beefed-up" our autism navigation process by implementing a more robust team approach. We recently hired a full-time Advancement Coordinator to help increase revenue to assist with our need to expand infrastructure. And we have a new Spanish Translator position that we are hoping to fill soon. SPARC has finally selected an Electronic Medical Records system and we are busy learning, teaching and setting the platform up. If anyone has gone through this before, you know it's not a fun or easy process.

Children's Therapy Center

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

No updates at this time

Health Plan Updates

Amerigroup-Washington

Jackie Matter

www.amerigroupcorp.com

No updates at this time

[Coverage Area Includes: All Counties except Adams, Chelan, Clallam, Clark, Cowlitz, Douglas, Ferry, Grant, Kittitas, Lincoln, Okanogan, Skamania, and Wahkiakum]

No updates at this time.

Community Health Plan of Washington (CHPW)

Kristol Parker, Manager, Case Management

www.chpw.org

[Coverage Area Includes All Counties except Clallam, Columbia, Garfield, Jefferson, Klickitat, Lincoln, Mason, Skamania, and Whitman]

Medicaid Case Managers were trained on CYSCHN resources.

Coordinated Care

Sherry Bennatts, RN Manager for Care Management

www.coordinatedcarehealth.com

As many as 18 million people nationally could lose Medicaid coverage* during this public health emergency

“unwinding,” so we are promoting awareness internally and externally as we work together to keep Washingtonians covered.

Molina Healthcare of Washington
Mary Blakeman and Margaret Whaley

www.molinahealthcare.com

No updates at this time.

UnitedHealthcare
Cindy Spain and Mandy Herreid

www.uhc.com

[Coverage Area Incudes: All Counties except Clallam, Cowlitz, Garfield, Pend Oreille, San Juan, Skagit, and Whatcom]

No updates at this time.

Partner Updates

Washington State Parent to Parent Network

Tracie Hoppis

<https://arcwa.org/>

1. New host agency serving Kitsap/Jefferson Counties- South Sound Parent to Parent; new Coordinator is Kimberly Adams
2. Presentation at Infant and Early Childhood Conference featuring Multicultural Coordinators from across Washington. Presentation will be in Spanish (the first time in history of IECC) and English translation will be available. Coordinators will share programming information and family stories.
3. Working with DOH around development of Type 1 Diabetes program; providing peer support for parents/caregivers raising children with Type 1 Diabetes
4. Preparing for annual May Coordinator's training (in-person!) where we will feature networking and training opportunities for around 45 Parent to Parent Coordinators from across Washington, including DOH Community Health Worker Training presentation.

Washington State Medical Home Partnerships Project for CYSHCN

Kate Orville

www.medicalhome.org

No updates at this time.

University of Washington CSHCN Nutrition Project at CHDD

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

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

No updates at this time

Washington State Fathers Network (WSFN)

Louis Mendoza

www.fathersnetwork.org

No updates at this time.

Family to Family Health Information Center (F2FHIC)

Jill McCormick

www.familyvoicesofwashington.com

*During this quarter F2F has been; * working with Pediatrics Northwest on understanding family engagement within their practices and developing a plan to start and grow family participation in developing a family centered care model, * is participating in the ACCELERATE project, * is participating in the T1Diabetes workgroup and developing a resource page for the group, * still administrates the WSLI website and logistics for the group * finished up the final year of the CoIIN project (anyone wanting more information on that can email me) * finished our 3 reports for HRSA Showing a significant increase of support in both our duplicated and unduplicated count across all categories. Thank you for all of the hard work within this group that supports the work around our CYSHCN families and young adults in our State. If anyone would like more detailed information on our numbers, you can email jmccormick@wapave.org.*

Open Doors for Multicultural Families

Hodan Mohamad

www.multiculturalfamilies.org

No updates at this time.

Washington Autism Alliance & Advocacy (WAAA)

Arzu Forough

www.washingtonautismadvocacy.org

Our weekly Special Education legal clinic for low-income families:

washingtonautismalliance.org/events/special-education-legal-clinic/?occurrence=2022-10-06&time=1665059400

and Enhanced Behavior Support Homes campaign at the upcoming meeting?

washingtonautismalliance.org/enhanced-behavior-support-homes/

Office of Superintendent of Public Instruction (OSPI)

Nicole Klein, Health Services Program Supervisor

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

No updates at this time.

School Health Services (OSPI)

Annie Hetzel, School Health Services Consultant

<https://www.k12.wa.us/student-success/health-safety/school-health-nursing-services>

Updated Home Hospital Guidelines for Schools. In progress: updates to Guidelines for Care of Students with Diabetes and Infectious Disease Control Guide for Schools. Providing professional development for school nurses on Section 504 Disability Rights.

Seattle Children's Hospital

Paula Holmes

www.seattlechildrens.org

No updates at this time.

Lifespan Respite Washington (LRW)

Linda Porter

www.lifespanrespitewa.org

No updates at this time.

WithinReach

Chris Gray

www.withinreachwa.org

No updates at this time.

Alliance CaRES

Christa Murray, Community Engagement Coordinator

The Alliance CaRES program, supports foster parents and kinship caregivers as they travel the foster care journey, walking alongside the youth in their care. We have specific groups and mentors to support foster parents and kinship caregivers who are caring for a medical complex youth.

State Updates

Department of Children, Youth, and Families Early Support for Infants and Toddlers (DCYF-ESIT)

Lori Holbrook

www.dcyf.wa.gov/esit

State Interagency Coordinating Council

January Special Session: The special session was held on January 18, 2023, to review the status of the drafted FFY 2021 Washington State Performance Plan. Performance on and metrics used for 11 indicators were reviewed and new targets confirmed for both compliance and results indicators.

Regular Quarterly Session: The winter quarterly meeting was held on February 15, 2023. Guest speakers from the Arc of King County included Zack Siddeek, Disability Systems Navigation Coordinator; Peter Jung, Information & Resources Coordinator; and Jae Kim, Supervisor of Information and Referral. Together they addressed “Disability is Diversity” and supported the council members in exploring important topics including • Disability Rights is Civil Rights • Respectful Language • The Different Forms of Disability and • The Models of Disability. SICC Agendas and Minutes are available on the agency website.

Comprehensive System of Professional Development (CSPD) Strategic Planning Launched

Insights from Regional Provider Meetings: During a two-week series of regionally based provider meetings held in March 2023, community partners had additional opportunities to learn more about and provide input on the new Initial Universal Training Framework and planned training opportunities.

Statewide Data Management System Highlights

New Landscape: In fall of 2022, DCYF ESIT and the Public Consulting Group (PCG) began their collaborative work on the ACORN (Access to Child Records Network) migration project. The project will happen in phases, beginning with the replication of current functionality and data migration.

Training Plans Under Development: In anticipation of the go-live date, we are cross-teaming with PCG and DCYF IT Training to develop the ACORN Training Plan for the new system. Based on user feedback, we will be using a three-tiered approach to training including Universal (statewide for all), Targeted (i.e. regional or User-type), and Tailored (i.e. individualized based on unique needs). Our project plan accommodates a 30-day training window prior to the release of ACORN.

Washington State Blueprint for Planning & Designing an Integrated Monitoring System

Drafted Vision Statement: The Washington State IDEA Part C statewide monitoring system will ensure equitable service provision with a balanced focus on compliance and improved outcomes for all children and their families and collaboratively align the needs, priorities, and related monitoring requirements of state early intervention partners.

ESIT Statewide Integrated Monitoring System (E-SIMS): The new statewide monitoring system focuses on the integration of fiscal, compliance, and performance requirements. All ESIT Provider Agencies engage in a variety of monitoring activities every year, including the submission of data and fiscal reports, Desk Top Compliance Reviews, Fiscal Integrity Reviews, and designation of Determinations. The newest component under development, the Systems Analysis Program Reviews (Onsite Visits), will be implemented using a scheduled 2–3-year cycle, with the opportunity to engage sooner as may be needed or requested.

DSHS, Developmental Disabilities Administration (DDA), Kelly Temby-Sturtevant, NCC

<https://www.dshs.wa.gov/dda/>

No updates at this time.

DSHS / DDA, Medically Intensive Children's Program Doris Barret

No updates at this time.

DSHS, Fostering Well-Being Care Coordination Unit (FWB CCU) Autumn Wade and Amanda McCleskey

No updates at this time.

DSHS / ALISA, Kinship Care and Lifespan Respite Rosalyn Alber

www.dshs.wa.gov/kinshipcare

No updates at this time.

DOH Screening and Genetics Unit Nini Shridhar

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

No updates at this time.

Health Care Authority

No updates at this time.

Attachments

- Agenda ([PDF](#)) ([wa.gov](#))
- Meeting presentation slides ([PDF](#)) ([wa.gov](#))
- Meeting recording ([youtu.be](#))
- **Care Coordination Family Advisory Council** ([English](#)) ([Spanish](#))

Next Meeting

July 13, 2023

9am – 1pm

Virtual Meeting