

### **COMMUNICATION NETWORK MEETING**

October 14th, 2021

### **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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	Holly Ridge Center serving Kitsap and North Mason Counties is currently serving approximately 320 month. We are completing evaluations and serving children and their families via tele-health using Zoom platform. We do have some children that come into our center for in-person services due to needs.	a HIPPA compliant very specific
	We are currently using the CDC transmission rate tracker to adjust services in our area. We are gat regarding Vaccine status so we can be in compliance with the vaccine mandate by October 18 <sup>th</sup> . W	-
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## **Attendees**

Due to continued social distancing requirements enacted by Governor Inslee, Communication Network will be conducted entirely in an online format.

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Guests:	
Mari Mazon, The Community-Based Feeding Team	
Same and Blaire, Parent Voice	
Sarah Sahl and Darren Janzen, OHSU	

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

www.doh.wa.gov/YouandYourFamily/InfantsChildren and Teens/Health and Safety/Children with Special Health Care Needs. as pxing the control of the control o

#### **Staff Updates**

#### Child Health Intake Form (CHIF) Database

The import feature is live in the CHIF database. If your agency is regularly updating CHIF with large data volumes, the import feature may be an option to reduce your administrative time. This feature allows agencies to export data from their Electronic Medical Record system into a csv. file, and then upload that file into CHIF directly. If you are interested in learning more about this, please reach out to Sarah Burdette for additional support and training.

For more information, contact Sarah Burdette at 360-688-3251 or sarah.burdette@doh.wa.gov.

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

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

#### **CYSHCN Program Nutrition Updates**

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

#### CSHCN Rule (Washington Administrative Code-WAC) Update

For more information, contact Monica Burke at 360-236-3504 or monica.burke@doh.wa.gov.

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

For more information, contact Marilyn Gisser at 360-236-3503 or see <a href="www.doh.wa.gov/efc">www.doh.wa.gov/efc</a>.

#### Universal Developmental Screening (UDS)

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

#### **MCH LHJ Contracts Updates**

For more information, please contact Mary Dussol at 360-236-3781 or mary.dussol@doh.wa.gov.

#### **Guest Presentations**

#### The Community-Based Feeding Team

Improving the Lives of Children, Youth, and Families

Mari Mazon

What is Pediatric Feeding Disorder?

It is not defined well until recently. There are a variety of different concerns and it's hard to tell difference between a typical picky eater and a feeding disorder. Pediatric Feeding Disorder was just recently defined as an impaired oral intake that is not age appropriate. This has been updated as an available ICD-10 code this year.

ARFID and Eating Disorder are DSM V diagnoses, PFD is medical diagnosis. A distinction is that eating disorders often present in older children and a disturbance in body image, but PFD can be associated with a medical event or difficulty with swallowing. In addition, diagnosis can include medical dysfunction, such as difficulty with heart rate or aspiration during eating. A variety of different specialists may diagnose/treat this.

Registered Dietitians can address malnutrition (growth), nutrient deficiencies due to restrictive eating, reliance on a feeding tube, and relying on shakes or supplements

OT SLPs PTs address feeding skills using tools such as thickened liquids or a particular texture, modified feeding positions, and distraction during meals.

Psychologist, ABA, counselor, and/or social workers may address psychosocial Dysfunction such as avoiding being fed (active - pushing away or passive -talking, falling asleep), disruption of caregiver child relationship around feeding, and social functioning impaired during feeding. Such providers are important but difficult to find in some communities.

PFD can be inconsistent with cultural norms and expectations because it doesn't have cognitive processes related to eating disorder.

Screening is completed through an ICFQ -Feeding Matters Infant and Child Feeding Questionnaire; there is also a 6 question screen for birth to 3 with an online version that adjusts for prematurity.

#### Treatment:

The WA State feeding Team has a minimum of a RDN and a feeding therapist, some are at a single agency, some are interagency. They are working to fill gaps; reach out to Mari or Sarah Harsh if you know someone interested in this work that is not connected.

There is a new website and new toolkit by Feeding Matters for providers

#### Questions:

Would GI issues - constipation/ diarrhea also be a medical component as part of the dx? Yes, it would

Are feeding teams county, regional, or community based?

Depends on the team e.g, ESIT catchment area, NE region cover larger geographic area

Does the nutrition network website for finding nutrition providers show when providers have expertise in behaviorally driven eating like ARFID or is this resource mainly showing RDNs with more medical expertise in pediatric feeding dysfunction?

It shows those that have taken our training and continuing education in feeding CYSHCN. So it is fairly broad right now. Planning for future being able to have their areas of expertise listed

Does the directory have a way to indicate if a specific provider offers telehealth nutrition services options?

Yes, that is listed in the current directory - may need to scroll to the right

At what point do you stop oral feeding therapy when a child is not responding?

On a case by case basis. Sometimes a pause is helpful to relieve pressure. Joint decision between families and providers

How can I access a feeding team so I can refer a child from my CSHCN caseload or MD referral? How is this different from a nutritional referral to Childrens or Mary Bridge?

Refer to early intervention - families can self-refer

#### **Parent Voice**

Parent Voice: Story of Silas and his Feeding Adventure

Our son Silas Finn Shainsky was born on April 28, 2020, weighing 1 lb 15 oz, and 14 inches long. Just one month after the world shut down due to COVID-19. And just 25 weeks, 3 days into our pregnancy. First-time parents have enough unknowns to anticipate. Now we had to navigate the uncertainty of giving birth at the end of our second trimester.

Throughout the night while I was in labor we had so many questions, will our baby survive? What will he look like? What choices would we have to make?

Once Silas was delivered, the 8-person NICU team immediately put a breathing tube down his throat, and began administering him breaths. I held him for a matter of seconds before he was placed on the transit isolette and was whisked straight up to the level 4 NICU with Sam and the team. I had just delivered my baby, and he was taken away from me.

We spent the next three nights in the hospital recovering, visiting Silas and stepping into our roles as NICU parents. We celebrated the small milestones like naming our baby, changing his diaper for the first time, and cheering for his first bowel movement! A couple weeks later, we really started to get into a groove. We became constant at Silas' bedside. We developed a rapport with our doctors and nurses through our consistency, curiosity, and our advocacy.

Not just to understand Silas' course, but to be the champions of our child's medical journey. We quickly learned that Silas' sole focus at this point was to breathe. Sounds simple right? As the curious parents we were, we learned the ins and outs of every respiratory device that Silas may or may not need to transition to along his journey towards room air.

Silas' advancement in his breathing course brought us to early July, which was our official green light to experiment with bottle feeding for the first time. We were so excited! This was 70 days after Silas came into the world. 70 days that Silas had been fed exclusively through an NG tube. Receiving a full belly, every three hours on the dot. And now, we were expecting Silas to continue his breathing progression, but to add bottle feeding into the mix.

We were determined. We would be there to feed him ourselves 3 times a day. Our world revolved around Silas, and we were going to do whatever it was going to take to bring him home. It was a slow progression. Our primary nurses would often encourage us by saying maybe Silas would turn a corner as he inched closer towards the 40 week milestone. Unfortunately, Silas' August due date came and went. With Silas still in the NICU, and no discharge date in sight, we were running on empty. But we knew we had to keep charging forward for Silas.

Eventually, he transitioned to room air and it was a huge accomplishment. He had mastered breathing and was doing really well. This meant that the only thing keeping Silas in the NICU was feeding. We had come SO far. He kept falling short of meeting the steps required to advance in the feeding protocol. We couldn't get into a groove. We felt this pressure around every single bottle attempt. What we weren't told - and what we think now is such a missed opportunity - is the transparency from the NICU. Which would have been the reality that micro-preemies, babies born before 26 weeks, can have a longer and strenuous feeding course that can commonly result in longer term feeding challenges.

We were assigned to an SLP who came by once a week, mostly when we weren't around, which was disappointing given how consistent we were about our visits. The SLP had no concrete advice beyond the basics on how to improve Silas' feeding situation. Most importantly, the SLP never communicated the realities of going home on a G-tube. It almost felt like nobody wanted to bring it up to us, as if they were waiting for us to bring it up to them. As if they were waiting for us, the mentally exhausted, completely deflated, non-medically trained NICU parents to propose something that we knew nothing about. We were familiar with NG tubes, because Silas had one for a long time. But we learned through prodding that they didn't send babies home with NG tubes unless they knew it was temporary.

Putting myself back in that moment, I did NOT want Silas to go home with a G-tube. What parent would? We were the parents always there, ready to support and nurture Silas; however, we weren't medical experts, with professional training. There was so much that we didn't know about the journey of a feeding-challenged micro-preemie.

We will never forget sitting in a room with a doctor, charge nurse, and discharge coordinator looking at a doll with a PEG tube. For those of you who may not be familiar, this is not your typical G-tube button. This is a long, 12-inch plastic tube that comes out of the stomach. It was so big on this tiny doll's body. I felt my eyes swelling with tears and I began to cry. I couldn't believe this was our journey, and my child who had come so far needed this to go home. Heading into this meeting, I mentally prepared myself for Silas getting a G-tube button, because I could visualize it. But now I felt completely unprepared hearing the team recommend something that looked so foreign. Their reasoning for the PEG tube made logical, medical sense. So we signed off on it.

We weren't just signing off on the celebration of finally bringing our baby home, but a surgery that would send us back up to the level 4 NICU for post-op, the floor that we'd worked so hard to graduate from. We were signing off on a permanent scar in our son's stomach, a scar that he'll have to explain when his friends ask him what's that mark? We were also signing off on becoming medical parents without even knowing what that entailed. And in the next three days, Silas would have the PEG tube surgery, and we welcomed him home after 136 days in the NICU.

We worked exclusively with our new team, checking in as often as we needed. Beginning the program allowed us to feel reinvigorated with a new plan - working with a team that was invested in our shared goals. There was a clear long-term vision. And we knew that pursuing this would progress us and give us more clarity of what Silas was capable of.

We learned the importance of having a coordinated team among our feeding therapist and dietician. We finally felt like we struck gold because we felt supported and we knew that Silas was supported too. The wean journey was very intense, and there was a lot of uncertainty at many checkpoints.

We are very proud to share that Silas' wean was successful and the last time we used his tube was February. We've discovered that for Silas, eating and drinking is a learned skill. It continues to take a lot of repetition for Silas and a lot of patience for us. Silas continues to receive weekly feeding therapy sessions and continues to improve, but on his own time.

Even though we have ignited Silas' appetite and can pick up on his cues for hunger now, we are not out of the woods. We find special meaning in small moments, like Silas taking his first bite of pizza last week, and loving it. Along with him taking continuous sips in a row from his straw cup. It is a beautiful phenomenon that Silas controls his meals and calorie intake now. We eat meals as a family (when we can!), and we look forward to creating more memories around food together.

In reflection, the hardest part of Silas' feeding journey was that we had no experience on a path that is so specialized by professionals who have dedicated their careers to supporting children with feeding challenges. We truly are grateful for every person who worked with Silas and for what they provided. Though we often felt like we were being asked to lead on a journey that was so uncharted for us.

We understand that the NICU's goal is to send babies home. But they sent Silas home with a PEG tube in his belly and no direction or a plan for eventually getting it out. It's as if it is so much easier to make the decision to put the G-tube in, but once it's in, good luck finding a path to getting it out.

We never felt like we had someone who was the champion of our family from the beginning. We were seeking a level of overall commitment from someone who was invested and willing to help us wean off his tube, someone willing to dive in, poke holes, and understand what was preventing Silas from finishing bottles. At the end of the day, we championed Silas' journey. Oftentimes it felt like we were the only ones who wanted Silas to be an oral eater.

#### Questions:

His G-tube is not out, and he has been gaining weight. They haven't used his G-tube since February, and plan to take it out in February. Have transitioned him to a button which is easier to manage.

When discharged from NICCU they did not recieve recommendations about who to reach out to next other than the dietitian. They didn't get information that they recommended early intervention. When discharged, they didn't have any guidance about who to connect with and the dietitian didn't share any resources with them about who to connect with or best practices recommendations.

#### What is ARFID

Oregon Health and Sciences University

#### Darren Janzen and Sarah Sahl

Pediatric Feeding Swallowing team is multidisciplinary for families which is shown to be best practices for complex feeding support work. Some in the team are psychologists, dietitians, occupational therapist, lactation consultants, and GI specialists

Avoidant Restrictive Food Intake Disorder (Red flags, when to refer, roles, and expectations for success)

DSM-5 (2013): changed the way we think about mental health diagnosing, it is based on scientific advancement and research in mental disorders. AFRID assigned in the new DSM-5.

#### **AFRID**

Used to be "eating disorder", but it didn't have the language to reference accurately. AFRID is similar to anorexia, but very different in intention. AFRID references individuals who are not worried with body image and weight. A person with AFRID doesn't eat enough calories to grow and develop properly and in adults they don't consume enough calories to maintain body function.

Diagnosed when: eating/feeding disturbance leads an individual to not meet proper nutritional needs

Children with Autism Spectrum Disorder, ADHD, and anxiety may be more likely to develop AFRID.

#### Pediatric Feeding Disorder (PFD)

PFD is defined as a disturbance in intake of nutrients for children under 2 years old.

There are similarities between ARFID and PFD but also differences. PFD is framed as a disability and ARFID is NOT framed as a disability. ARFID is common to be associated with a mental disorder. ARFID stems from the mental health arena and defined in DSM while PFD is rooted in medical and developmental realms.

\*Important to help families understand different pathways to get to these diagnoses

#### **Conditioned aversion**

Conditioned Food Aversion can be a learned association that a taste of a food is a cause of an illness (fatigue, nausea, worry). Brains look for connections in an attempt to keep them safe. For kids, when there is a negative association, it can have induced a fight or flight association. A meaningful way to heal over conditioned food aversion is to make a neutral or positive association with the food.

#### **Investigative Process**

It is helpful to use multidisciplinary team to determine the areas of concern (organics/behavioral processes). This can be done by gathering additional data through interviews and use team-based decisions to develop approaches to resolve issues.

Note: negative reinforcement is a part of operant conditioning (BF Skinner)

Reinforcement Styles: Positive: something added Negative: something removed They are working on escape extinction, but not allowing avoidant behavior so new associations can form. The encourage working to be positive and patient in the process. Their intention is to stop negative cycle that moves patients away from avoidance to teach kids to learn to do hard things in a slow and safe environment.

It generally takes about 2 years for a child with AFRD to get evaluated. Why does it take so long? Developmental screening tools are not sensitive to feeding difficulties.

Who is vulnerable?

Genetic- super tasters

Evolutionary advantages to food preferences

Experience shapes perspectives-if a child is limited in what they eat, it can make other foods taste even more unusual

Some people are more vulnerable to begin this pathway and continue the pathway as well.

Behavioral Clues through questions that foster openness and trust:

- 1. Describe what happens during mealtime?
- 2. What do you do when child doesn't eat?
- 3. How stressed are you about child's eating?

Family feeding styles: Controlling, responsive (best), indulgent, neglectful

Barriers that keep Patients Stuck

Sensory sensitivity, fear of aversive consequences, lack of appetite or low interest in eating

Sensory sensitivities: lack of hunger and/or fear of negative consequences present in patients with ARFID

\*Co-morbid conditions are often present- ASD, ADHD

Goals: To lay a foundation for therapy for ARFID

Treatment Interventions:

Sensory Sensitivity

Systematic desensitization through steps to eating

Fear

Work to create fear ladders to push back against fear to help kids learn to feel safe Patients and parents work to learn they have control over their fears

Limited Appetite

Put kids on positive meal and snack schedule (alarms) avoid grazing to help with a stomach full/empty sensation

Encouraging patient to tolerate somatic experiences that may be uncomfortable with eating

#### **ARFID** and Malnutrition

Nutritional Assessment:

Description of mealtimes

**Growth Chart** 

Vitamin and Mineral intake

Medical complications that could manifest as ARFID when could be something else Description of mealtimes\*

What are the nutritional unknown?

It's okay to give some acceptance of poor diet quality, and know there is a preference for hyper processed and high carb foods and low in "whole foods"

Tools: Growth for ppl with AFRID- ppl come in all shapes and sizes Growth chart is not an effective tool to diagnose condition

Variety restriction: only eats a limited number of foods (health weight or over weight status)

Volume and variety restriction

Post Traumatic food intake restriction (ex: choking)

Health Eating Index Score

Score 100 suggests all foods supported with Dietary guidelines

General population score is 53% which is still failing

Helpful context for families with AFRID parents to reduce stress

Prevalence of severe medical complications of AFRID

Only 76 severe medical complications from AFRID

Nutrition that are big players: Vitamin C 72%, then vitamin A, b12, D, and thiamin

Common nutritional deficiencies:

Vitamin D, Iron, Calcium, and Zinc

Interventions Nutrition:

Fortified foods, supplements(Multivitamin), milk consumption

Hard to make meaningful change and may take a long time to make that change

Even in private programs designed to support AFRID-no change or significant change in

increasing the variety and number of foods that increase from feeding treatments

Medical: Consider lab work- food allergies, esophagitis, etc.

Diet: provide reassurance when possible, try to avoid oral nutritional supplements (such as Pedialyte)

unless there is a deficiency in both nutrients AND calorie and nutrient intake

Goals: refer to therapy- build confidence to support and learn healthy behaviors

What can be done?

ICFQ-Infant and Child Feeding Questionnaire Screening tool

Evidence based tool that is free for kids under 36 months

Refer to Community Therapy

Occupational/Speech Therapy/Behavioral and Mental Health Support

Management

Safe eating!

Use medical(labs and screening)

Use RD (reassurance and supplements)

Use OT/SLP (structures and skills)

Psychology: recognize and treat co-morbid mental health conditions, support behavior

modification for both parent AND child

## **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

Our program has a new program coordinator who is cleaning up our CHIF data, sending out renewals and connecting with past/current CYSCHN families and new referrals. We have updated our brochure and will be updating our department CYSHCN webpage to include a link to our referral form and brochure.

We have connected with our neighboring Pacific County Public Health CYSHCN program to expand a SMART program for both counties. We have a team of local service providers, including a medical provider that is a COE, to help with developing documents and communication materials for the program. We are improving referral pathways for families who are looking for support around Autism diagnosis and/or need evaluation. We have also been working to connect local medical providers to COE training.

Our CYSHCN staff are supporting The ARC of Grays Harbor with the implementation and hiring of a new Outreach Coordinator position focused on engaging families and caregivers in the Hispanic/Latino community who have children and youth with an intellectual and developmental disability (IDD). This position will improve engagement with the educational and support opportunities The ARC provides and reduce barriers to local services for people with IDD and their families across any language and cultural barriers.

The Program Supervisor for our CYSHCN and Home Visiting program is engaged in Help Me Grow work that is happening at a statewide, regional and local level. She is participating in statewide Help Me Grow action teams that focus on Child Healthcare Provider Outreach and Family and Community Outreach. The supervisor is also involved in the regional and local early learning coalition where the work of these Help Me Grow action teams will be used to create coordinated resource and referral systems.

#### **Barriers/Successes:**

Connections with local medical providers are tricky right now due to the focus on COVID and now flu season. We are trying to talk through meaningful ways to connect with providers with the purpose of supporting their work with families of CYSHCN.

Grant County Health District
Julia Austin, RN, BSN, Public Health Nurse

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

Jefferson County Public Health
Apple Martine, Community Health Director

## Pacific County Children and Youth with Special Health Care Needs Princess Klus, Care Coordinator-Family Navigator

## San Juan County Kristen Rezabek, MS, RDN, CD, CDE

ESIT-10, CYSHCN -41. San Juan received funding to support a part time Dental Access Coordinator and continue the mobile dental van project with Medical Teams International in 2022. The Smile Mobile is coming to Friday Harbor November 2-5. Our San Juan Autism County Collaborative (SJCAC) SMART is ready to start accepting children for autism evaluation and review. We are still working on how to structure some of the diagnostic tests/ tools if they are warranted as our providers have concerns regarding using ADOS given the limited number of clients they would see in our county and being able to maintain fidelity.

Our food access program funding and support from the community has been robust and responsive to the increased needs we are seeing across our county. We are hopeful that with the launch of the Help Me Grow WA campaign there may be trainings and CME provided events to promote UDS within the Health Care Provider setting.

Our concerns with the current status of Help Me Grow is that for small rural counties using the statewide Coordinated Access Point (CAP) does not reflect all the local resources and services available and may serve to disenfranchise families and providers who attempt to connect via this system and come away with limited information or supports.

Exploring the possibility of creating a feeing team in conjunction with Island County. ARPA funds recently approved by County Council to help support Early Learning Programs providing ~\$500 per enrolled child for each eligible center as well as helping support stand up emergency supports services including new cooperative preschool models on Lopez and San Juan and an afterschool program on Lopez which are much needed for families to ensure access to care.

#### Spokane Regional Health District

Workgroup created with community stakeholders to address gaps in services for families in Spokane County. This has resulted in a collaborative partnership with community advocates, establishing a Parents Empowering Parents virtual support group.

Participating in Spokane Equipment Sharing Network to create library of durable medical equipment that families can access to determine if works for their child and/or to use while waiting for insurance/DDA approval.

Co-facilitating the Birth Outcomes Taskforce which focuses on upstream interventions for healthier birth outcomes and promoting racial equity in maternal health in Spokane. This group consists of hospital partners, subject matter experts, child welfare, and primary care practitioners.

Continued Work First assessments for families who have children with special healthcare needs.

Continued navigation of families into Early Support for Infant and Toddlers (new title of the Infant Toddler Network) program and help to access community supports.

Collaborating with Early Support for Infants and Toddlers and the Nurse Family Partnership.

### Thurston County Public Health and Social Services

Since the Neurodevelopmental Program at Mary Bridge started entering CHIF, I have not received referrals from Mary Bridge. I contacted Mary Bridge at the Neurodevelopmental Program asking for referrals for our county's CYSHCN program.

I have been consistently receiving 6-8 Work First referrals per month.

Our MCH team will be receiving IMH trainings from Gina Veloni PhD, MN, RN, IMH for the IMH-E.

Our county was chosen for a mini grant from DOH for the Essentials for Childhood Inventory of What Works project. We collected information throughout our county through a survey to develop a landscaped asset inventory to capture evidence based, trauma informed, racial equity for promising practices, policies, and programs to prevent child abuse and neglect and strengthen family resiliency. We were able to identify policy strategies with strong focus on early childhood strategies.

CYSHCN coordinator, NFP nurses, outreach educational specialist, opioid response coordinator along with other outside community partners have been working on the Pregnant and Parenting strategies piece for TC Opioid Response Task Force.

Our goal is to reduce exposure and access to opioids among infants, children, youth, and families. Our strategies were to: expand access to local family planning services to reduce neonatal abstinence syndrome (NAS) and integrate breastfeeding best practices for women with opioid use disorder into services that have direct contact with pregnant and parenting women. We developed a small card that has a few resources for women who may be pregnant and want help and support. Pregnancy tests will be attached to these cards and be distributed throughout the county.

Yakima County- Children's Village Tracie Hoppis

## **Neurodevelopmental Center (NDC) Updates**

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

Children's Therapy Skagit Valley Hospital Erin Kaui Lead Therapist

www.skagitvalleyhospital.org

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

www.valleymed.org

We are seeing a great upheaval in schedules with kids going back to school. Good they are back in school, but challenging related to scheduling and we are working on this to the best of our ability. Lots of increased sick calls from families as well.

We have an open 1.0 newly approved OT position and are searching for the right new team member.

We are seeing a significant decrease in the number of PMBS studies we have done and are looking at this program closely. We have only done 4 this year. Your feedback is greatly desired as we look at whether it makes sense to continue this service at VMC.

We participated in the NICU read-a-thon and a Facebook fundraiser which raised over \$1000 for our Books for Babies program which promotes early literacy and sends a book home with each baby.

Our free Art Therapy Thursday's group has restarted for anyone in the community – 12-1pm.

### Kindering

#### Kathy Fortner Director of Operations

#### www.kindering.org

Kindering, now approaching its 60<sup>th</sup> year, provides leading-edge therapies and special education for infants and toddlers with disabilities, delays, and other risk factors from sites in Bellevue, Bothell and Renton, and Redmond. These services range from inclusive preschool programming and speech, feeding, and motor therapies, to supporting young children experiencing homelessness or living in foster and kinship care, as well as a range of family support services for parents and siblings of children with special needs. Since March 2020, Kindering has offered our therapies and supports both virtually and in-person, supplying the necessary technology to families who need ways to access our services from their homes.

#### **UPDATES:**

- Kindering is excited to be expanding our services to include children who are deaf and hard of hearing but have no other developmental needs. Previously, D/HH children and no additional developmental needs were served through other agencies. Now, we will offer specialized Family Resources Coordination and partner with other organizations for services as needed. We're happy to be able to offer these services and reach more children in our community.
- For the 5<sup>th</sup> year in a row, Kindering made the Puget Sound Business Journal's List of 100 Best Workplaces! Our staff are resilient and inspiring, and it's because of their hard work that we are one of the few (if not the only) nonprofit organizations on this list.
- We are hiring! Kindering has open opportunities for a Communications Specialist, Family Resource Coordinator, Speech and Language Pathologist, Therapy Aide, and more! Direct service provider roles and admin/operations roles available. See all current job postings at <a href="Kindering.org/Careers">Kindering.org/Careers</a>.

**UPCOMING COMMUNITY EVENTS:** Kindreing's 16<sup>th</sup> Annual Salute to Courage fall fundraiser is Friday, Oct. 22. Join us on your lunch break at 12 p.m. at <u>youtube.com/kinderingcourage</u> for an inspiring program. You'll hear an organization update from CEO Dr. Lisa Greenwald, heartwarming family stories, and a keynote address from Sheila Ater Capestany, King County's Strategic Advisor for Children and Youth and Director, Children, Youth and Young Adult Division. RSVP and give at <u>kindering.org/courage2021</u>

#### **HOLLY RIDGE**

#### Alicia Skelly, Infant Toddler Program Director

Holly Ridge Center serving Kitsap and North Mason Counties is currently serving approximately 320+ children a month. We are completing evaluations and serving children and their families via tele-health using a HIPPA compliant Zoom platform. We do have some children that come into our center for in-person services due to very specific needs.

We are currently using the CDC transmission rate tracker to adjust services in our area. We are gathering information regarding Vaccine status so we can be in compliance with the vaccine mandate by October 18<sup>th</sup>. We are currently looking to hire a Social Worker, OT, part time PT and an RBT.

#### Children's Therapy Center

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

Children's Therapy Center serving South King and North Pierce counties with both early support services (ESIT) and clinic based services for children 3-18. Our clinics in Burien, Kent and Tacoma are seeing families in person and through tele-health. We have resumed some small in person group experiences a for children and families with special Covid adaptations. This includes social skills friendship group, gymnastics group and fitness center group. Our therapeutic aqua program is occurring at our community partner Waterbabies pool in Renton.

Our ESIT programs are operating on a "blended" model with most families receiving services partially in person and partially through tele-health. Special education groups have resumed in person options with special Covid adaptations. Virtual supports for children and families continue as well. We have several open positions available throughout our organization and would love to talk to potential candidates. Please see these on our website at <a href="https://www.ctckids.org">www.ctckids.org</a>

## **Health Plan Updates**

### Amerigroup-Washington Jackie Matter

www.amerigroupcorp.com

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

#### **Clark County:**

Kathy Fockler is doing a wonderful job in her role as Clark's CYSHCN nurse. She has a heart for families and kids and is a natural fit for this position! Kathy finds it rewarding to assist families in navigating complex systems and to connect to resources. Kathy carries a large caseload and would love to have a community health worker as part of the team when/if funding allows in the future.

Other news is that Pat Shaw is retiring Dec. 1. Pat has been with CCPH since 1993 and was the CYSHCN nurse from 2003 to 2007. Pat took a management position in 2007 and has overseen the CYSHCN program since then.

Pat will send update with successor's name/contact info once they are identified/hired.

#### **Okanogan County:**

**Key System Projects:** 

- Contacting families, updating files, providing education regarding remote access to services to families, reaching
  and connecting to several families whose children with special health needs and/or family members tested
  positive for COVID
- Working with ESIT and local Early Childhood Pre-K programs to increase awareness of health education to families.

#### **Challenges Facing**

• Increase incident case numbers in county with COVID – balancing workload. Missed several meetings because of conflicts with schedule.

Big Barriers/Needs they are hearing from Families and providers

- Providers are reporting children behind/missing well child exams and immunizations compared to years past. \*
- Parents report struggles with some zoom platforms in areas that have slow/intermittent internet services and disappointment in not having personal visits with specialists /therapists. \*
- Rescheduling/long waits for service providers since COVID
- Vaccine mandates affecting staffing shortages in several local clinics. Many families placed on virtual visits or had visits/appointments rescheduled.
- Decrease in access to services rumors of closure of some companies that provide durable medical goods in the county.

#### Success stories

• Families report use of internet platforms for joining support groups – better, feeling more inclusive

#### **Staffing Updates**

• One nurse and one bilingual CHW – continue to provide communication with families.

### Community Health Plan of Washington (CHPW)

www.chpw.org

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

No updates at this time.

Coordinated Care
Sherry Bennatts and Azka Bashir

www.coordinatedcarehealth.com

## 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 ]

**SPARC of Skagit Co.** is currently operating under the guidelines of the local health department. We are offering inperson preschool services and a variety of in-person and virtual services for our Birth-Three services. We are currently looking to recruit a Family Resource Coordinator and a Certified Special Education Teacher to our team.

### **Partner Updates**

### Washington State Parent to Parent Network Tracie Hoppis

### Washington State Medical Home Partnerships Project for CYSHCN Kate Orville

www.medicalhome.org

#### **Autism Systems work**

- **COE training:** Next virtual Autism Center of Excellence (COE) Certification training is Friday December 10th- please share with your clinician partners. CSHCN public health nurses and others supporting clinicians diagnosing children and youth and connecting them to services are also welcome to participate. COE Registration Page-https://medicalhome.org/coe
- **Project ECHO Autism WA:** 72 Primary care provider and psychologists from across WA are participating in Project ECHO Autism (last year it was 28). The next cohorts will start in January 2022- MDs/DOs/ARNPs/NDs have to have gone through the COE training to participate in ECHO. Kate and Sophie participate as public health/community partners' connectors. <a href="https://uw-ctu.org/echo/">https://uw-ctu.org/echo/</a>
- School and Medical Autism Review Teams (SMART): We now have monthly SMART networking calls where a
  highlighted team shares what they are doing- Pacific, <u>Thurston</u> and <u>Island County</u> SMART teams have shared
  updates in the past quarter. Welcome to Jefferson, Benton and Cowlitz Counties which have new planning efforts
  started! There are now 21 communities in some stage of developing community-based interdisciplinary evaluation
  teams using the SMART model. Additionally, King and Pierce COEs do not have SMART teams but are piloting
  different approaches in collaboration with early intervention centers.
- Map of COE, ECHO and SMART teams: <a href="https://medicalhome.org/wp-content/uploads/2021/06/wa-echo-smart-coes.pdf">https://medicalhome.org/wp-content/uploads/2021/06/wa-echo-smart-coes.pdf</a>

#### **Southwest Washington Autism Conference**

## Register TODAY!

The 11th annual **Southwest Washington Autism Conference** will be held November 10 and 17, 2021 via Zoom.

The <u>full conference schedule</u> is available at the Conference website. There are 3 sets of live workshops and several pre-recorded ones to choose from.

- Many <u>autistic presenters</u> including Siena Castellon, Marcelle Ciampi, Chris Tiana, Obey Sumner, Ivanova Smith, Jeremy Kaufman, Tanner Calder and Audra Sisak.
- Educators! Practical strategies with tips and tools for teachers from McAlister Greiner Huynh, Kerri Blankenship, Dr. Jennifer Spencer-liams and Monica Meyer.
- Culturally-responsive services and racial justice topics presented by Dr. Carlos Mejia-Rodriguez, The Equity Institute and Chris Tiana Obey-Sumner.
- Parent support workshops featuring Darla Helt, Dena Alt, Jerri Clark and Victoria Romero.

*Scholarships*!! Available to Lewis County autistic adults/teens, parents and educators. Before you register, contact Victoria Romero to apply for a scholarship at thelinkcoordinator@outlook.com or call (360)-508-4287.

Conference Website: <a href="https://www.lcautism.org/2021-sw-washington-autism.../">https://www.lcautism.org/2021-sw-washington-autism.../</a>
Questions: Email conference@lcautism.org

https://mailchi.mp/9b4ef83ee5d1/register-now-nov-10-17-southwest-wa-autism-conference-4851054?e=4469251592

## University of Washington CSHCN Nutrition Project at CHDD Mari Mazon, MS, RDN, CD and Sarah Harsh, MS, RDN, CD

University of Washington – Center on Human Development and Disability (CHDD)

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

The Nutrition Training contract between the CSHCN Program, DOH, and CHDD-UW, provides training and technical assistance to registered dietitian nutritionists (RDNs) that are part of the CSHCN Nutrition Network, and to Community Feeding Teams, as well as projects related to improving nutrition through medical nutrition therapy and feeding team services.

#### **Nutrition Network (NN) Training and Development**

1. <u>Nutrition Network Meeting</u> – Planning has begun for Nutrition Network meeting 2022. It will be held via Zoom on Monday, May 16, 2022. Keynote speaker will be Raquel Durban, MS, RD, LD/N who will speak on nutrition management for IgE-mediated food allergies.

#### **WA Community Feeding Teams**

1. WA State Community Feeding Teams Meeting – Planning has begun for WA Community Feeding Teams meeting 2022. It will be held via Zoom on Tuesday, May 17, 2022. We will have an interdisciplinary feeding team from Growing Independent Eaters talk about feeding tube weaning.

#### **Hospital to Home Transition**

1. <u>Hospital to Home Work Group</u> – We are in the process of planning a series of follow-up workshops for the 6 feeding teams that attended the pilot 3-day Hospital to Home training. We are also looking into offering another 3-day Hospital to Home training for the 9 remaining teams that had applied.

#### Nutrition Interventions for Children and Youth with Special Health Care Needs Publication

We are updating this publication, which was last revised in 2010.

## Washington State Fathers Network (WSFN)

#### Louis Mendoza

www.fathersnetwork.org

- Virtual Webinars were held on the following subjects:
  - o An Introduction to the Office of the Education Ombuds and Resources for Parental Advocacy
  - Helping Our Children Develop Meaningful Relationships
  - o Financial Strategies
- Work continues with the Seattle Cultural Accessibility Consortium to connect arts and culture organizations with the information and resources to improve accessibility for people of all abilities. The Consortium Connections

- and Workshop sessions will now focus on creating a space for dialogue between staff of cultural organizations and individuals from the disability/special needs community.
- Work continues with the WA Interagency Fatherhood Council. New programs include the Dads Allies Provider Series and Dads Connect. The first of the Dad Allies series was on the importance of fathers in the perinatal period. The Dads Connect series will start October 20 and are opportunities for dads to come together and talk about important issues that affect fathers and families.
- Was a member of the group who planned and conducted the WSLI conference: Hand in Hand: Coming Together to Support Diverse Families. My role was to moderate a panel of parents.
- Spanish language broadcasts were held on Supporting Children with Feeding Challenges and Bilingualism and Language Development.
- Continue to work with the WA Chapter of the American Academy of Pediatrics First Year Families program and the Accelerating Child Health Transformation team to impact best pediatric practices.

## Family to Family Health Information Center (F2FHIC) Jill McCormick

www.familyvoicesofwashington.com

No updates at this time.

### 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

No updates at this time.

## Office of Superintendent of Public Instruction (OSPI) Nicole Klein, Health Services Program Supervisor

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

## 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.

## **State Updates**

#### Department of Children, Youth, and Families

Early Support for Infants and Toddlers (DCYF-ESIT)
Lori Holbrook

www.dcyf.wa.gov/esit

Updates from the ESIT State Office – October 2021 Will Moncrease, Jr. Accepts New Leadership Role



Please join us in welcoming Will Moncrease, Jr., in his new position as the ESIT Partnership and Collaboration Manager (previously titled Stakeholder Engagement Manager). Will is a decorated Army Veteran and dynamic early learning professional with the compassion to see in others what they cannot see in themselves. He is dedicated to representing communities most directly impacted by the social injustice of education inequality. Will believes people are our foundation, and what we seek in our communities is what we find in ourselves. Relationship building is at the heart of what he continues to prioritize as a means of strengthening intentional collaborations with local, state, and

tribal partners to build systems that actively support each and every child and their family to excel. These attributes, characteristics, and values will help Will as he takes on responsibility for leading the development, design, and sustainability of a statewide family, community, and stakeholder engagement system to support ongoing systems improvement efforts focused on improved outcomes for young children and their families.

#### The ESIT State Office is Recruiting for a Regional Technical Assistance Specialist

The ESIT state office is seeking a Regional Technical Assistance Specialist who lives in and serves the northwest region of our state. This position supports cross-team work for the ESIT program within the Family Support Programs Division and provides specialized, expert-level technical assistance and coaching on behalf of Washington's state lead agency for Part C of IDEA, which is DCYF. This position is responsible for supporting Early Intervention Provider Agencies in one of four regions statewide in all program activities, ensuring the consistent implementation of all aspects of early intervention services while maintaining the required elements of state and federal early intervention laws and regulations in a manner consistent with DCYF values including integrity, compassion, transparency, respect, and inclusion. Posting for this and other positions available at DCYF can be found online.

#### State Interagency Coordinating Council Seeks Candidates for Committee Vacancies

Are you interested in supporting critical work and sharing your insight, experience, and perspective on important areas of the ESIT system? SICC is actively recruiting candidates for the following committees:

- Finance
- Personnel and Training
- Public Policy Committee

Interested persons are encouraged to apply by completing this application. If you have questions, please contact Will Moncrease, Jr., ESIT Partnership and Collaboration Manager, at will.moncrease@dcyf.wa.gov.

Parent Institute for Engagement (PIE): Cohort 4

Nine individuals were selected to participate in the latest cohort of the Parent Institute for Engagement (PIE). Members of Cohort 4 represent different counties across Washington State, including King, Island, Kitsap, Spokane, Pierce, and Thurston. PIE's first meeting with Cohort 4 will be held on Tuesday, Oct. 19.

For additional information about PIE and other family leadership opportunities, please contact Vanessa Allen, ESIT Family Engagement Coordinator, at <a href="mailto:vanessa.allen@dcyf.wa.gov">vanessa.allen@dcyf.wa.gov</a>.

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

No updates at this time.

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

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

Scott Wilson joined the FWB team on August 2nd, 2021 as our Social and Health Program Consultant 2. Prior to FWB, Scott worked at Aging and Long-Term Care and at CPS as an afterhours worker. Additionally, after grad school Scott was a lawyer for parents and kids in dependency cases, he then switched to social work. He currently lives in Yakima with his two dogs. He likes golfing and hiking around the state.

Dr. Chris Sadler joined the FWB team on April 1, 2021 as one of our part-time Regional Medical Consultants (RMC) in Region 1 and is available to DCYF and tribal social workers for clinical consultation. She is also a practicing pediatrician (part-time) in her local community. Dr. Sadler has an extensive background working in the pediatric field and has experience as an instructor, designing remote case-based learning sessions.

Scott Wilson will be joining the CYSHCN meetings starting in October.

## DSHS / ALTSA, 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)
- Meeting presentation slides (PDF) (wa.gov)
- Meeting recording (youtu.be)

The attachments can also be found on the CYSHCN Website

## **Next Meeting**

January 13th, 2022

Virtual Meeting