

CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM

COMMUNICATION NETWORK MEETING

July 14, 2016

CSHCN Program Mission: To promote integrated systems of care which assure the population of children with special health care needs the opportunity to achieve the healthiest life possible and develop to their full potential.

CSHCN 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.

Attendee	Phone Number	Email Address
Kevin Cornell, Health Care Authority (unable to attend)	360-725-1423	kevin.cornell@hca.wa.gov
Colette Jones, Health Care Authority	360-725-1782	colette.jones@hca.wa.gov
Cary Robertson, Amerigroup-Washington (unable to attend)	206-695-7081, ext. 54552	Cary.Robertson@amerigroup.com
Melissa Shilipetar, Community Health Plan of Washington (unable to attend)	206-613-5086	melissa.shilipetar@chpw.org
Elizabeth Allen, Coordinated Care	253-442-1428	elallen@coordinatecarehealth.com
Sherry Bennatts, Coordinated Care	253-442-1543	sbennatts@coordinatedcarehealth.com
Cathi Sears, Molina Healthcare of Washington	800-869-7175, ext. 147148	catherine.sears@molinahealthcare.com
Nikki Nordstrom, Molina Healthcare of Washington	800-869-7175, ext. 147141	nikki.nordstrom@molinahealthcare.com
Cindy Spain, United Healthcare (unable to attend) Janelle Sorrell represented UHC	206-749-4347	cindy_l_spain@uhc.com janelle_sorrell@uhc.com
Jacquie Stock, CCSN at Seattle Children's (unable to attend)	206-987-3729	jacquie.stock@seattlechildrens.org
Kate Orville, Medical Home Partnerships for CYSHCN (unable to attend) Amy Carlsen attending on behalf of MHPP	206-685-1279	orville@uw.edu carlsa@uw.edu
Sharon Feucht, University of Washington, Nutrition Program	206-685-1297	sfeucht@uw.edu
Louis Mendoza, Washington State Fathers Network	425-747-4004, ext. 4286	louis.mendoza@kinderling.org
Susan Atkins, Washington State Parent to Parent	1-800-821-5927	parent2parentwa@gmail.com
Jill McCormick, Family to Family Health Information Center	253-565-2266	jmccormick@wapave.org
Yissel Ortega, Open Doors for Multicultural Families (unable to attend)	206-372-1072	yisselo@multiculturalfamilies.org
Robin Fleming, Office of Superintendent of Public Instruction (unable to attend)	360-725-6050	robin.fleming@k12.wa.us
Marianne Bastin, Good Samaritan Hospital, Children's Therapy Unit, Neurodevelopmental Centers Representative	253-697-5200	marianne.bastin@multicare.org
Debi Donelan, DEL, Early Support for Infants and Toddlers (ESIT)	360-725-4400	debra.donelan@del.wa.gov
Jamie Bond, DSHS, Developmental Disabilities Administration (unable to attend) Nicole Ferguson represented DDA	360-725-3466	jamie.bond@dshs.wa.gov nicole.fergason@dshs.wa.gov
Adam Clarno, DSHS, Fostering Well-Being	360-725-9593	adam.clarno@dshs.wa.gov
Hilarie Hauptman, DSHS, Kinship and Family Caregiver Program (unable to attend)	360-725-2556	hilarie.hauptman@dshs.wa.gov
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Chris Zipperer, DOH, Office of Healthy Communities	360-236-3614	chris.zipperer@doh.wa.gov

Guests:		
Elisabeth Long, Department of Health		elisabeth.long@doh.wa.gov
Lara Sokoloff, UW LEND Fellow		



Children with Special Health Care Needs (CSHCN) Program Update

Maria Nardella

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

CSHCN Program Updates

Staff Updates: Healthy Starts & Transitions (See *Attachment #1* for PowerPoint presentation.)

Flu Prevention

The Flu Influenza Fact Sheet (see *Attachment #2*) for children with special health care needs has been updated to comport with the latest CDC recommendations. This will be available online as soon as the multiple language translations are done in Spanish, Russian and Vietnamese.

MCH Block Grant

Our annual Maternal and Child Health (MCH) Block application, report and review are coming to a close this summer.

MCH Stakeholder Input: DOH is conducting a statewide survey of families and parents/caregivers to get feedback on services provided. Please forward this survey link to families and individuals who are impacted by MCH services:

<https://fortress.wa.gov/doh/opinio/s?s=10174><https://fortress.wa.gov/doh/opinio/s?s=10174>

We want to get as much feedback as possible from those served through the Maternal and Child Health Block Grant and other funding sources. If you are able to add a link to your webpage, as well, that would be helpful in spreading the word. Here is sample language, in case it is helpful:

We are all committed to improving the well-being of our state's parents, babies, children and youth—and the communities in which they live. [Insert your organization's name] has been asked by the Washington State Department of Health to gather feedback on the work they are currently doing. Your input will help guide their work in the future. [Take the survey.](#)

DOH MCH staff reviewed initial comments July 7th for the July 15th grant application submission. Very few responses were received from families with children with special health care needs. The survey will close August 30th in preparation for the September 15th final grant submission. If you have any questions about the survey or MCH Block Grant, please contact Rabeeha Ghaffar at Rabeeha.Ghaffar@doh.wa.gov or 360-236-3634.

State DOH Budget Update (Maria to complete)

DOH focus on Foundational Public Health Services

Joint ask possible with DEL to promote Kindergarten Readiness

Upcoming New Grants

1. Early Childhood Comprehensive Systems – we found out this week that our proposal was not accepted. We haven't heard yet which of the up to 15 states were awarded. We will have to determine how the staffing and Help Me Grow/Universal Developmental Screening efforts can continue without the ECCS grant funds.
2. Autism Spectrum Disorders & other Developmental Disabilities = "AS3D" – if awarded would start September 1, 2016.

Family Leadership Update – Michelle Hoffman

DOH has partnered with several community based organizations and several state agencies to create a statewide network of trained family and consumer advisors to work in an advisory role to plan systems. We have been working to implement this network over the past 9 months. The group voted on a name for the network and voted for Washington Statewide Leadership Initiative-*family and consumer partnerships*. Our partnerships are across systems and at the local, regional and state level. We are utilizing components of a collective impact framework and results based accountability. Next steps include:

- Creation of a data workgroup

- SharePoint site onboarding webinar for partners
- Common Agenda
- Charter
- Semi-Annual Leadership Initiative Meeting November 9, 2016

For more information about Family Leadership activities, please contact Michelle Hoffman at 360-236-3504 or michelle.hoffman@doh.wa.gov.

CSHCN Data Share Update

DOH is continuing to work with the HCA on the data sharing agreement. We are working on defining the data elements/data requirements for reports on developmental screening, neurodevelopmental centers, and information about the number of CSHCN flags in ProviderOne.

Transforming Clinical Practice Initiative (TCPI)

A new contract has been established with Yakima Valley Memorial Hospital to fund the leadership of the Medical Home Neighborhood Team for the TCPI grant being implemented in conjunction with DOH, WCAAP, and Molina. The purpose of the team is to expand medical homes for children and provide expert consultation on clinical-community partnerships and care continuums for children to impact the delivery of pediatric care to improve:

- Care coordination
- An integrated approach to co-management, care transitions, and communication between hospital, pediatric primary care, behavior health, and specialty care
- Community connections
- Family engagement
- Youth transitions from pediatric to adult care

The team is just starting to create its infrastructure, membership, meeting schedule, subcontracts, and work plan. If interested in participating, contact: Jackie McPhee (Jackie.mcphee@yvmh.org).

Essentials for Childhood (EfC)

The vision of Essentials for Childhood is, “*All children in Washington State thrive in safe, stable, and nurturing relationships and environments.*” Our commitment for Essentials for Childhood in Washington is that by 2025 there are measurable and significant improvements in children’s health, development and education outcomes and that equity gaps are eliminated.

The Essentials for Childhood Steering Committee is a cross-sector venue for collaboration to support safe, stable, nurturing relationships and environments for children. The Steering Committee is transitioning to a 3 co-chair structure, with co-chairs representing different sectors. Essentials will soon be recruiting a new, contracted Executive Director. The Executive Director will be an inspirational, adaptive leader who exercises influence to build consensus across divergent points of view, achieving commitment and cross-sector alignment of efforts to achieve the EfC common agenda.

Three workgroups are moving forward with strategies to support the EfC vision.

- **The Community and Stakeholder Education and Action workgroup** is developing an approach to support community ownership, impact, and action, and is informing, and to educate key stakeholders on brain science, ACEs and resilience that will :
 - Assess, understand, and collect information on current landscape across state & within workgroup
 - Inform a “2.0 NEAR Speakers Bureau” to spread information and educate
 - Create process & infrastructure to collect and share information that then shapes the overall goal

The workgroup is sponsoring two Somali Youth & Family Club community café conversations this summer.

- **The Systems, Services and Implementation workgroup** is building on the Help Me Grow framework and statewide partnership. They recently agreed to develop framework for HMG in communities; identify systems and policy barriers to connecting children to services; recommend state level changes; promote local innovations.
- **The Innovative New Policy and Financing workgroup** convened a subgroup of school superintendents which is working on a framework a for whole child/social-emotional approach that could be adopted by schools

EfC is also working on a gap analysis that will tell our Washington EfC story showing where there are investments and activity, where more is needed, opportunities and barriers, and connection to our priority North Star Metrics and Common Agenda. This analysis will help the Steering Committee, workgroups and partners align and prioritize efforts in support of the EfC Common Agenda.

For more information about EfC, please contact Marilyn Gisser at 360-236-3503 or marilyn.gisser@doh.wa.gov or see <http://www.doh.wa.gov/efc>.

Great LINCS (Links to Integrate and Coordinate Care) for CYSHCN Grant

Great LINCS is moving into its third and final year on September 1st. We are continuing to work with the Maxillofacial Review Boards on improving shared plans of care across the state within that population. DOH is working with review boards to conduct workgroups with family advisors to advance this effort. DOH also recently worked with ESIT to roll out a guidance around medical homes for Family Resource Coordinators. Great LINCS also continues to work with WithinReach to expand its capacity to be a resource for CYSHCN, with a greater focus on marketing in year 3.

For more information, please contact Allison Chee at 360-236-3526 or allison.chee@doh.wa.gov.

Great MINDS Grant Updates

Great MINDS is working on scheduling training this summer and has a renewed contract to continue conducting trainings into next year.

For more information, please contact Allison Chee at 360-236-3526 or allison.chee@doh.wa.gov.

Project LAUNCH Expansion

Project LAUNCH is moving along as expected. Currently, two communities have completed the 'Train the Trainer's ASQ Training. The third community will be trained the first week in August. The UDS Tool Kit developed during the first Project LAUNCH grant has been updated and two communities have received training on how to use the Manual/User Guide with the early learning providers. Both communities have given feedback on the UDS Tool Kit and revision are underway. Next steps, core workgroups in two communities are busy deciding which sites (early learning providers) would be the best fit for the work of Project LAUNCH. The state and local lead have met with WA-AIMH to begin the endorsement pathway process for early learning providers who are interested in being endorsed at a level 1 or 2. The final Expansion Plan has been submitted to the Feds. At the state level we are diligently developing an evaluation plan, which a draft will be shared soon to the Expansion Oversight Council.

For more information, please contact Sherry Trout at 360-236-3523 or sherrylynn.trout@doh.wa.gov

Systems of Care (SOC) Mental Health Integration Grant/WA State Mental Health System Change

A statewide Family Youth & System Partner Round Table (FYSPRT) Leadership Academy occurred in Yakima on July 25 and 26. The primary focus of this event was to strengthen partnerships and participation in the Children's Behavioral Health Governance structure at statewide, regional, and local levels. The next Statewide FYSPRT is scheduled on August 11. The publishing date for the WISe Manual version 1.7 has been postponed from June 30 to an anticipated date of end of July or early August 2016 due to continued work to incorporate comments and complete final edits. DOH participation in SOC work through this grant will end with the ending of the current grant cycle on September 30, 2016.

For more information, please contact Sharon Shadwell at 360-236-3572 or sharon.shadwell@doh.wa.gov.

Healthy Communities Consolidated Contracts Updates

DOH updated guidance related to the development of local MCHBG work plans for the 2016-2017 funding year. This guidance is an attempt to more clearly align the work of local contractors with the MCHBG National Performance Measures and Statewide Performance Measures chosen by DOH during the 2015-2016 funding year. New this funding year is the effort to collect information on the type of work happening at the local level to impact these measures in three targeted program areas (Children and Youth with Special Health Care Needs, Universal Developmental Screening, and Adverse Childhood Experiences).

The schedule for the 2016 MCHBG Regional Meetings is set:

- October 18 – Coupeville (Island County Health Department)
- October 20 – Vancouver (Clark County Health Department)
- October 25 – Spokane (Spokane Regional Health District)
- October 26 – Moses Lake (Grant County Health District)

Watch the MCHBG bi-weekly for updates and more information about the regional meetings and future topical calls.

For more information, please contact Chris Zipperer at 360-236-3614 or chris.zipperer@doh.wa.gov.

Special Presentation

Update on Blood Lead Screening of Children in Washington State
Elisabeth Long, Childhood Lead Poisoning Surveillance Epidemiologist, Department of Health

Elisabeth Long presented on Blood Lead Screening of Children in Washington State. See *Attachment #4* for PowerPoint presentation and Elisabeth's speaker notes. Elisabeth has given her permission to use her slides as needed. Elisabeth also distributed a handout entitled "Lead Screening Recommendations for Children in Washington State". See *Attachment #5*.

Elisabeth demonstrated the Washington Tracking Network Information By Location (link: <https://fortress.wa.gov/doh/wtn/WTNIBL/>) Or Google "WTN IBL" – click on "Lead Exposure Risk". Use the various tools to find relative lead exposure risk (based on housing and income- more weight on age of housing than income) of geographic areas. Mapping tool has different layers, such as county boundaries, school district boundaries, zip code, and you can show location of schools and licensed child care centers. This tool also has other data in addition to lead risk, such as social vulnerability, etc.

Question: What about lead in schools?

Answer: Washington is testing schools for lead in the drinking systems- for example, in Tacoma, the water SOURCE is fine, but as it travels through lead pipes or fixtures, that can be the source of lead. Schools are changing fixtures. A general best practice is to let your water run for 20 seconds first thing in the morning, every day, to flush the pipes. This flushes out the stagnant water, which would have the highest concentration. For formula-fed children, flush water until it's cool before using it for formula.

Question: Are you working with schools?

Answer: The DOH Office of Drinking Water is. In 2009, School Rule (environmental toxins texts, tripping hazards, etc.) passed in 2009 – but it wasn't funded so it was "frozen". Now, they are looking at re-opening sections of that rule, including lead. Lead paint is a much higher risk than drinking water, other than in extreme issues such as in Flint, Michigan.

Link to Governor's Directive on Lead: http://www.governor.wa.gov/sites/default/files/directive/dir_16-06.pdf

Health Care Authority (the Medicaid agency)

Colette Jones and Kevin Cornell

Updates from HCA's blog at www.HCA.wa.gov/hcaconnect that our partners can subscribe to for routine updates.

Smooth transition for enrolling foster children in managed health care

by Amy Blondin on 5/31/2016 3:42 PM

More than 22,000 foster and adopted children, and young adult alumni of foster care are now enrolled in Apple Health (Medicaid) managed care since we moved this population from fee-for-service on April 1. HCA is contracting with Coordinated Care to provide coordinated, whole-person care to these children and young adults.

Already since April 1:

- Coordinated Care has completed outreach on all 5,557 high risk members to complete an initial health screen. The screen helps them determine health care needs and the type of care management a member would benefit from.
- 1,142 members are now in active care management based on the Initial Health Screen results. The clinical team of nurses and licensed behavioral health staff have started contacting these members and caregivers to complete care plans and coordinate care for identified needs.

"Overall, and most importantly, we have definitely begun making a positive difference regarding health care coordination for this population, as we have already assisted hundreds of caregivers with finding resources, transportation, medications, and durable medical equipment for the foster population," said Dr. Jay Fathi, Coordinated Care president and CEO.

Fathi shared a couple early success stories:

- Our staff set up WIC, transportation and had a 3 way, hour long phone call including the PCP for a 9-month-old around health care coordination; the caregiver/grandmother who is legally blind cried and thanked us at the end of the call.
- One of our Case Managers supported a caregiver with a 2 y/o born with significant developmental concerns, including frequent head banging behaviors causing bleeding and injury to the child's head. Caregiver relayed that she was unable to access care as appointments to address this behavior were 3 months out, and she was very concerned about the child's safety in the interim. We instructed caregiver to take child to hospital to rule out significant head trauma. While caregiver and child were at hospital, Coordinated Care reached out to multiple providers and secured an appointment within the week for the child, and by the time the caregiver and child left the hospital, they had a plan in place. Caregiver was relieved and thrilled by the level of support and coordination from Coordinated Care to remove barriers to care, and meet this child's urgent/unique needs.
- From an Engagement Specialist at the Mockingbird Society: "I heard tons of feedback from the young people you talked with about how awesome you both were and how it was the one of the first times they've actually felt like they accomplished something with their health care because they could talk 1:1 with you. THANK YOU for making that possible."

The road to value-based purchasing

by Amy Blondin on 6/16/2016 1:33 PM

Part of our efforts to build a Healthier Washington is transforming the way we pay for health care from volume to value.

This week, HCA posted our value-based roadmap. It lays out the ambitious but achievable goal of linking 90 percent of HCA provider payments—through Apple Health (Medicaid) and the Public Employees Benefits Board (PEBB) Program—to quality and value by 2021. This follows the legislative directive to move away from paying per service.

How will we do this? The roadmap braids together major components of Healthier Washington, and is built on these principles:

- Reward the delivery of patient-centered, high value care and increased quality improvement;
- Reward performance of HCA's Medicaid and PEBB Program health plans and their contracted health care systems for increased adoption of value-based payments;
- Align payment and delivery reform approaches with CMS for greatest impact and to simplify implementation for providers;
- Improve outcomes for patients and populations;
- Drive standardization based on evidence and the common measure set;
- Increase long-term financial sustainability of state health programs; and
- Continually strive for the Triple Aim of better care, smarter spending and healthier people.

"We have set an ambitious path ahead, shifting 90 percent of state-financed health care payments to value-based purchasing within five years. But we are confident we will get there," said HCA Director Dorothy Teeter. "This document doesn't have all the answers, but rest assured we will keep the lines of communication open. We highly value and look forward to your continued engagement."

CMS announces new Medicaid managed care rules, HCA reviewing impacts on Washington Apple Health

In May 2016, the Centers for Medicare and Medicaid Services (CMS) published updated regulations intended to overhaul Medicaid managed care.

The new regulations will impact over 150 different federal rule provisions and span a multi-year implementation period, beginning with the first set of effective dates on July 5, 2016. According to CMS, the changes align key rules with those of other health insurance coverage programs, modernize how states purchase managed care for beneficiaries, and strengthen the consumer experience and key consumer protections.

The last update to Medicaid regulations occurred 14 years ago, in 2002. Since then, the nation's health care system has undergone significant change. Similarly, managed care plans have expanded to include a broader set of services and supports. Medicaid's managed care regulations are codified at 42 C.F.R. Part 438.

The Health Care Authority (HCA) is reviewing the impacts of the updated regulations and taking the lead to coordinate implementation efforts.

Additional updates provided at Communication Network Meeting

Skamania and Clark counties Molina and CHPW fully managed care programs rolled out in April. Integrating mental health, substance use and physical health under one plan. Will be doing more phase-ins in additional regions, more to come on this as information is available. In the rest of the state, mental health and substance abuse under Behavioral Health Organizations (BHOs) has replaced RSNs.

	<p>Health Plans Amerigroup-Washington Cary Robertson www.amerigroupcorp.com</p>
<p><i>[Coverage Area Includes: All Counties <u>except</u> Adams, Chelan, Clallam, Clark, Cowlitz, Douglas, Ferry, Grant, Kittitas, Lincoln, Okanogan, Skamania, and Wahkiakum]</i></p>	

Cary Robertson was unable to attend. No updates available.

	<p>Health Plans Community Health Plan of Washington (CHPW) Melissa Shilipetar www.chpw.org</p>
<p><i>[Coverage Area Includes All Counties <u>except</u> Clallam, Columbia, Garfield, Jefferson, Klickitat, Lincoln, Mason, Skamania, and Whitman]</i></p>	

Our care management team continues to work on care integration in Southwest WA. We will also be adding a few new clinical positions in the care management team over the next few months. Other than those items nothing new.

	<p>Health Plans Coordinated Care Sherry Bennatts www.coordinatedcarehealth.com</p>
<p><i>[Coverage Area Includes: All Counties <u>except</u> Clallam, Ferry, Kittitas, and Pend Oreille]</i></p>	

Identified a gap in care among children enrolled in multiple systems. Had an 8 year old CPS child not in school, nor connected to other needed. Families sometimes do not have ability to complete applications for services. Now have added a full-time social worker on staff to address these gaps in care. Elizabeth Allen is now Quality Improvement Coordinator at Coordinated Care, moving out of her previous role with foster care. Still supporting children in foster care and CSHCN. Foster Care managed care is going extremely well.

	<p>Health Plans Molina Healthcare of Washington Nikki Nordstrom www.molinahealthcare.com</p>
<p><i>[Coverage Area Includes All Counties <u>except</u> Island, Jefferson, Klickitat, Skamania, and Wahkiakum]</i></p>	

Increased CSHCN team by 1 FTE.

	<p>Health Plans UnitedHealthcare Cindy Spain www.uhc.com</p> <p><i>[Coverage Area Includes: All Counties <u>except</u> Clallam, Cowlitz, Garfield, Pend Oreille, San Juan, Skagit, and Whatcom]</i></p>
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Janelle Sorrell attended on behalf of Cindy Spain.

Healthy Rewards program started in July, incentive programs for members with certain conditions or situations. Exploring matching teen sports visits with annual check-ups.

	<p>The Center for Children with Special Needs (CCSN) at Seattle Children's Jacquie Stock www.cshcn.org</p>	 Seattle Children's <small>HOSPITAL · RESEARCH · FOUNDATION</small>
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[Seattle Children's Center for Children with Special Needs \(CSHCN.org\)](http://www.cshcn.org)

- **Emergency Preparedness and Children with Special Health Care Needs**—findings from literature review, expert key informant and community stakeholder input compiled into criteria state agencies and others may use to assess extent to which their plans address preparedness and response needs of children and youth with special health care needs. Questions? Contact Meredith.Pyle@doh.wa.gov.
- **Care Organizers**—in recent three month period, Maryam Jafari mailed 171 Care Organizers, including 11 Spanish language versions, to families around the state. **Whatcom, King and Benton-Franklin** counties were the top 3 requesting Care Organizers for families.
- **Summer Camp Directory 2016**—439 downloads from CSHCN.org alone (not including hard copy distribution).
- **Starting Point Guide**—resource for families offering where to turn for various needs was evaluated and improvements made based upon input from family advisors and health providers.
- **Linkages Newsletter**—theme specific electronic newsletter distributed to roughly 583 professionals in June on topic of juvenile diabetes. Three new videos on treatment and management of diabetes were posted to Seattle Children's online video library.
- **Families as Teachers**—six new family-medical resident and/or social worker matches were made for health providers to spend a “day in the life” with a child/youth with special need and their family.
- **Resource Fair Event**—Maryam Jafari represented CCSN at the May ARC of King County “Getting Organized” event, sharing our resources and information with attendees.
- **Social media outreach**—Paul Gilmore, CCSN Web Coordinator continues to expand CCSN social media outreach with currently 857 Facebooks “Likes” and 53 Twitter followers.
- **Family Online Needs Assessment**—In conjunction with WA DOH CSHCN program team, Kim Arthur, MPH and Beth Crispin, MS created questions to post on CSHCN.org on ongoing basis as a way to collect parent and family input about what type of information or resources they would like to see on CSHCN.org website.

<p>Medical Home Partnerships for CYSHCN and Their Families Kate Orville www.medicalhome.org</p>

Universal Developmental Screening

- **Harborview Developmental Screening Pilot:** We have been working since fall 2015 with Dr. Abby Grant and her colleagues at Harborview Pediatrics to improve their medical ‘homeness’, initially focusing on developmental screening for a vulnerable pilot group of young Somali children. This has broadened to helping the clinic develop a clear and smooth referral path for evaluation of their patients suspected of having autism and other developmental disabilities.

Great MINDs Developmental Screening in Practices Trainings

- Kate has been helping Edna Maddalena, Great MINDS training coordinator, identify and connect with potential new communities for training, including counties on the Peninsula and Eastern WA.

- Snohomish County public health nurses are doing a survey of pediatricians who took the Great MINDS training in 2015 to assess the impact of this training.

Community Asset Mapping (CAM)/Medical Home Leadership Network Teams

- Amy and Kate supported Susan Atkins, State Parent to Parent Coordinator, in organizing and facilitating a community resources meeting with Olympic Peninsula Communities to identify priorities and resources to better support local families and children on May 9, 2016. Twenty-five community stakeholders attended including Parent-to-Parent Coordinators and other family support groups, public health CSHCN coordinators, FRCs, DD Coordinators and others.
- This past spring, Snohomish decided to adapt the Spokane “Ask Now, Babies Can’t Wait” road map for use in their community. We connected them to Colleen O’Brien and Heather Wallace in Spokane. Jennifer Piplic, Verdant Foundation and CAM Steering Team member, went through the Spokane Regional Health District to confirm that Snohomish could adapt the brochure. The Snohomish brochure has been finalized in English and printed and will be translated into all the languages ESIT uses, plus Arabic. A template of these roadmaps will be available for use in other communities. Thank you, Spokane CAM workgroup for this great resource!

Medical Home Transformation Grant

- Kathy and Kate are participating in the WCAAP Health Care Transformation subcommittee. Kathy continues to participate in the WCAAP Early Childhood Subcommittee as well.

Child Health Note:

- We finalized the Child Health Note on postpartum depression that was posted in April <http://medicalhome.org/stateinitiatives/child-health-notes/>. We are in the process of updating the Child Health Notes on *Red Flags in Speech and Language Development* and *Speech Disfluency and Stuttering in Early Childhood*.

LEND:

- LEND will be piloting the “Adopt a County” initiative next year. The priority will be existing CAM communities, including Clallam, for the pilot. Through this pilot, LEND Fellows will have the opportunity to explore existing demographics, services and supports for CYSHCN in a community.

Conferences/Resources:

Check out our medical home website for a listing of many exciting conferences in the coming months <http://medicalhome.org/resourcessupport/training-calendars/>

Additional Updates Provided At Communication Network Meeting

Amy reported that their website was hacked recently and they lost the last 6 months of work on the site (hadn’t been backed up in that long.) So it’s up now, but info may be a bit old, are working to update everything.

Questions? Contact Kate Orville (orville@uw.edu) or 206-685-1279, or Amy Carlsen (carlsa@uw.edu), or Kathy TeKolste at (kat423@uw.edu).

University of Washington CSHCN Nutrition Project at CHDD

Sharon Feucht

depts.washington.edu/cshcnut/

Nutrition Network for CSHCN

On April 25th 61 Nutrition Network Registered Dietitians Nutritionists attended the spring workshop. The morning session was devoted to a presentation and hands on demonstration about blended tube feedings covering when these would be used, how to identify children that may be appropriate for this type of feeding in their gastrostomy feeding tube, meeting nutrient needs, and tips for parents and clinicians. The session ended with a parent panel describing their experiences with home blended tube feedings. The Network members also heard an update on nutrition research related to children with autism and how feeding therapy can benefit, and an update on new research in food allergies including guidelines for peanut desensitization in selected children. Program updates are provided from the CSHCN, WIC, Healthiest Next Generation, and Healthy Eating Active Living.

WA Community Feeding Teams

Eighty eight members of feeding teams from around the state attended their spring meeting on April 26, 2016. An extensive presentation was provided about dysphagia in young children, identification and options for treatment. A review

of thickeners that may be utilized, at times for dysphagia, was presented with pros and cons for use and product information. Information about requesting reimbursement for medical nutrition products from the WA State was reviewed. Other topics for the day included use of food chaining and how this can be implemented as a feeding therapy technique, a case study, and an update of the CSHCN program.

Transitions for Fragile Infants from Hospital to Home

On June 10th 4 parents and 23 providers met to discuss issues surrounding the transition of fragile infants from the hospital to home regarding feeding and nutrition issues. Concerns regarding lack of coordinated care planning, inadequate transition planning, need and access to more training for professionals to work with fragile infants regarding feeding and nutrition, and more were shared by providers and parents. A summary of all concerns was made and will be sent to those who attended to rank their top 10 priorities. Future discussions will be determined after responses are received.

Questions? Contact Sharon Feucht (sfeucht@uw.edu) or 206-685-1279, or Mari Mazon (lilmaro@uw.edu).

 The logo for the Washington State Fathers Network features three stylized human figures in black and white. To the right of the figures, the text "WASHINGTON STATE FATHERS NETWORK" is written in a sans-serif font, with "WASHINGTON STATE" on the top line, "FATHERS" in a larger font on the middle line, and "NETWORK" on the bottom line.	<p>Washington State Fathers Network (WSFN) Louis Mendoza www.fathersnetwork.org</p>
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Below are some of the notable items that took place or began in the last quarter:

- Representatives of WSFN, Dads Move, D.A.D.S. and WA Dads met and agreed to begin working together to serve dads of children with special needs. Initial efforts will be referring dads to other groups as appropriate and cross publicizing group activities and supporting those activities when possible either financially or logistically. The groups will meet quarterly to continue discussions on how to work together. The next meeting is scheduled for August 21st.
- Collaboration is occurring between WSFN, The Arc of King County, Dads Move, D.A.D.S. and WA Dads to create a closed Facebook group for dads who have children with Special Needs. It's expected to launch in early July. Dads can search Facebook for P2P Dads of Special Kids and request to join.
- The Network held its annual Father's Day weekend campout. 40 people attended including members of 5 new families.
- Conversations have begun with the Western Washington Girl Scouts and King County Boy Scouts about promoting scouting to families of children with special needs. The topic has been well received and conversations and work continue. Both organizations feel they are inclusive but admit they can do a better job communicating to families and training staff/volunteers/troop leaders. The organizations feel that this issue is one that they may be able to work on together.
- Planning has begun for a summer BBQ and Fish Fry to take place on August 6th at Judkins Park in Seattle. This will be a joint effort of the Network and The Arc of King County.
- A free photo event was held for dads and their children in Woodinville on March 15th. 23 dads made reservations and 18 took part. The professional studio, the time of 3 professional photographers and the photos were all provided at no cost to the families.
- A new video for the Network was completed and publicized. Two versions were produced one at 4 minutes and 30 seconds and one at one minute and 3 seconds.
- The Bellevue YMCA respite pilot program effort continues. At this time the target is to offer a program starting in October of 2016 that will run on Saturdays from 3:00-6:30 PM for children of middle school age. The project has caught the attention of YMCA management and, depending on the success of the pilot; the plan is to have future Y facilities in King County open with a respite care program. Long term the hope is to serve as a model for Ys in WA.
- Along with the Director of Dads Move, I attended the June JBLM Exceptional Family Member Program focus group. This was the first time that this meeting focused on men. As a lead in to the meeting I contributed an article to the programs June newsletter.
- A Helping Parent mentor training program geared for dads was held at and conducted by the Arc of King County on June 4 and 11. This program was based off of feedback from a focus group of dads brought together by the Network and the ARC to evaluate how the existing program, attended primarily by moms, could be more appealing to dads. 5 dads attended.
- The Spring edition of the Network newsletter was published on June 1.
- Plans have begun for the Network annual conference. We are partnering with the Bellevue School District. The event will take place on October 8th at Tyee Middle School in Bellevue. Presenters and the keynote are being scheduled. Plans are being finalized to be able to offer interpretation in Spanish and ASL.



Washington State Parent-to-Parent (P2P)

Susan Atkins
www.arcwa.org

With the new Parent to Parent statute and funding from the legislature we were able to establish 3 new Programs and also providing a little more DDA funding for each of the other 19 Programs as of July 1, 2016. See *Attachment #6* for a current Parent to Parent Site Roster.

Also, see *Attachment # 7* for a list of the Transition Trainings hosted by Parent to Parent Programs across the state. I thought it would be a good idea for everyone to see the many transition topics available for parent trainings.



Family to Family Health Information Center (F2FHIC)

Jill McCormick
www.familyvoicesofwashington.com

Overview:

The Family to Family Health Information Center is in the 2nd year of a 3 year grant cycle and has completed a very successful year in partnership with Parent to Parent, DadsMOVE, and Jeanette Barnes in supporting them in providing trainings and outreach in 14 counties as of March our impact numbers were up to 1095 families and youth and 316 professionals in topics such as care coordination, mental health parity, autism supports, behavior de-escalation techniques, seeking help from a Dads perspective, transition needs when looking at adult care for young adults, and many more information offerings. I will finish our full year impact report by July 19th if anyone would like our year end numbers.

Activities:

- PCORI grant the Patient Centered Outcome Research Institute grant that includes Family Voices from Idaho and New Mexico as partners and Washington has worked with the Muckleshoot Tribe and Sea Mar in this project and completed Tier II in March. We submitted for a Tier III award and were accepted as of July 1st, 2016. We are in the planning stages of this two-year award. We were also part of a panel at the national level with Open Doors to share outreach into vulnerable communities.
- We completed our project as a Community Outreach Collaborative with the National Disability Navigator Resource Collaborative with the American Association on Health and Disability, Family to Family continues to have access to the site and the staff for expertise in enrollment, plan choice and disability. The web address is <http://www.nationaldisabilitynavigator.org/about/>
- Participation in the Statewide Family Youth System Partner Round Table (FYSPRT) committee and the Washington State Community Connectors (WSSC) as these groups work on improving family and youth voice in our states mental health systems. Family to Family participates as a contract provider for the Salish Behavioral Health Organization (formerly Kitsap RSN) and now have a dedicated coordinator out of the PAVE office who lives in northern Kitsap County.
- Family to Family is a planning committee member on the Seattle Indian Health Boards Circles of Care grant and a new South Sound Native Community Coalition.
- Partnered with DadsMOVE area Head Starts and local community groups to do a family fun day and resource fair in Omak that reached 155 families and will do a second one in August in Tonasket. Anyone wanting to partner on this talk with Jill.
- Participation on Statewide Disability Emergency Preparedness Committee.



Open Doors for Multicultural Families

Yissel Ortega
www.multiculturalfamilies.org

Yissel Ortega was unable to attend. No updates at this time.

Office of Superintendent of Public Instruction (OSPI)

Robin Fleming
Program Supervisor for Coordinated School Health
healthyschools.ospi.k12.wa.us/waschool/

Robin Fleming was unable to attend. No updates at this time.

Neurodevelopmental Centers (NDCs) Update

Marianne Bastin, Good Samaritan Hospital, Children's Therapy Unit

www.birthtothree.org, www.boyercc.org, www.childrensdevelopmentalcenter.org, www.ctckids.org,
www.goodsamhealth.org, www.hollyridge.org, www.kindering.org, www.multicare.org/marybridge/developmental-services,
www.theprogresscenter.org, www.providence.org/everett/, www.sparckids.org, www.skagitvalleyhospital.org,
www.guildschool.org, www.peacehealth.org/st-joseph, www.valleymed.org, www.yakimachildrensvillage.org/

Children's Therapy Unit & Mary Bridge

What's new: continuing to improve access to care with quicker evaluations and entry to therapy. YTD 72% of children received an eval or started treatment within 30 days of referral. Adding many groups for social skills and motor skill development as appropriate. Pilot group of staff are now trained to give the WeeFIM as an outcome measure.

New staff: hired new COTA, (looking for additional COTAs and PTAs, speech therapist,) new OT supervisor at Mary Bridge, new NNFU case manager Samantha Swanson is replacing Janine Wakeley who is retiring.

New services: Maxillofacial Review Board now supervised by Angela Kitzmiller, hired new RN case manager.

Other news: refreshing PT and OT space at Mary Bridge with new flooring and paint. Expanding CTU orthotics to Mary Bridge. Looking for additional treatment space.

Brief overview of our program –Hospital based NDCs providing PT, OT, Aquatics, Speech, Audiology, Neonatal Follow up, Mental Health, Orthotics, Assistive Technology, Movement Lab, Research, Professional and Parent Education programs. Serving children 0-18 years. 5700 patients per year. 60,000 patient visits.

Holly Ridge Center

Holly Ridge Center, the only NDC on the Olympic/Kitsap Peninsula, is embarking on a Capital Campaign to purchase an additional site. The numbers of children served through Holly Ridge has continued to increase, averaging 355 active IFSP's every month. The new site will allow us to bring our Adult Employment Program and Infant Toddler Program back under one roof, thus giving up two current rental spaces. With the numbers of children increasing, so has our number of staff. We are very excited to now have both a Teacher of the Visually Impaired and a Teacher of the Deaf/Hard of Hearing on staff, as well as the state's first licensed Infant Mental Health Provider! Our ARNP of 30 years, Patti Schroeder, is retiring in August. She will be greatly missed. We are currently looking for a part time ARNP/BSN as well as a certified Early Childhood Special Educator and a Para-Educator.

Kindering Center

Kindering's enrollment continues to grow. In May Kindering served over 1,000 children in our combined programs. Kindering provides Early Intervention IDEA Part C services, private therapies for children over age three, Parent Child Home Program visits for low income families and integrated preschool classes. Kindering's Autism specific ABA classroom called CUBS has expanded and is now offered in our Bothell office as well as Bellevue. Alegro Pediatrics and Kindering Speaker Series is offering classes in *Raising a Child with Special Needs* and *Advocating for Your Child*. Sibshops are offered at both the Bellevue and Bothell offices. See *Attachment # 8* for Kindering's Newsletter or www.kindering.org for more information.

Two exciting Kindering events are planned in the coming months. "August Nights" a wonderful wine and ale tasting event at McMenamins Anderson School in Bothell is scheduled for August 4th. Kindering's Fall luncheon the 11th annual "Salute to Courage" is scheduled for October 6th at the Grand Hyatt Bellevue featuring keynote speaker Ross Hunter, Director of the Washington State Department of Early Learning. For more information on either event, go to <https://kindering.org/getinvolved/events>.

Valley Medical Center

- What's new: We have begun a new collaboration with RAYS (Renton Area Youth Services) now have an MSW on site on Fridays.
- New Staff: We hired a new SLP...need a new rehab aide and per diem PT (positions are posted)
- New services: MSW – counseling
- Other news: Remodeling waiting room, adding new treatment space
- Brief overview of our program –Hospital-based NDC; 0-18; 1800 clients; OT/PT/SLP/RD/MSW

Children's Therapy Center

Jon Botten, Director of CTC, is leaving. They will be recruiting for his replacement.

 <p>Washington State Department of Early Learning</p> <p>Early Support for Infants and Toddlers</p>	<p>Department of Early Learning Early Support for Infants and Toddlers (DEL-ESIT) Debi Donelan www.del.wa.gov/esit</p>
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ESIT Staff Updates: Alma Quinden started as the new Parent Engagement Specialist on July 11. Alma has a bachelor's degree in psychology from the University of Washington, Tacoma and Master's degree in psychology counseling from Walden University. Past experiences include social worker with the department of aging and disability, family advocate and family support specialist with early head start and ECEAP, as well as extensive experience working with children with special needs in school settings as a paraeducator and substitute teacher. Most recently Alma served as the director/manager of a residential program in King County for homeless children. Alma has a strong background in childhood mental health, serving children and families with special needs as a therapist for 10 years, which included working in conjunction with school district social workers to ensure children with special needs received timely screenings and providing input on the development of appropriate education plans. Alma's commitment to serving children and families spans 20 years of direct service in the community, which makes her a great asset to our team. Please add alma.quinden@del.wa.gov to your email list and help us welcome her to the ESIT statewide program!

ESIT Determination – Meets Requirements: This year's annual determination from the federal Office of Special Education Programs (OSEP) validates that Washington Part C "Meets Requirements". The framework includes results data in addition to compliance data.

Legislative Update: *Last session, the Legislature passed [SB 5879](#), which requires the Department of Early Learning (DEL) to develop recommendations for the "redesign" of the Early Support for Infant and Toddlers (ESIT) program. In the past several months, DEL has been actively gathering information from stakeholders and consulting with national technical assistance centers to approach our requirements in the most effective and thoughtful manner possible.*

Section 6 of this legislation requires the department to develop and submit a plan to the Legislature on comprehensive and coordinated early intervention services for all children eligible for ESIT (Part C of the federal Individuals with Disabilities Education Act). The proposed plan is to include, but is not limited to:

1. A full accounting of all the expenditures related to ESIT from both DEL and school districts, as collected by OSPI;
2. The identification and proposal for coordination of all available public financial resources within the state from federal, state, and local sources;
3. A design for an integrated early learning intervention system for all eligible infants and toddlers who have been diagnosed with a disability or developmental delays and their families;
4. The development of procedures that ensure services are provided to all eligible infants and toddlers and their families in a consistent and timely manner; and
5. A proposal for the integration of early support for infants and toddlers services with other critical services available for children birth to age three and their families.

To date, we have surveyed our Local Lead Agency (LLA) staff and school district contacts, gathered feedback at LLA meetings and at our State Interagency Coordinating Council meeting, researched other state's systems and rules, facilitated a question and answer session at the Infant and Early Childhood Conference, and met with several states to learn from their systemic successes and challenges. Next steps will include drafting rules, continuing to gather stakeholder feedback (including meetings with an OSPI stakeholder group), and to create a draft proposal to present to stakeholders. Dates for upcoming feedback opportunities are listed below:

- Starting Strong Conference, Tacoma Convention Center, August 3, 10:30 am (open)
- Special Education Conference, Hotel Murano, Tacoma, August 4, 10:00 am (open)
- Special Stakeholder Meeting, August 23, 9:00-3:00 (by invitation)

Data Management System (DMS): DMS information on system updates and enhancements is provided through GovDelivery: <https://public.govdelivery.com/accounts/WADEL/subscriber/new>. Users are encouraged to sign up to receive the most up-to-date news regarding the DMS.

Family Resources Coordinator (FRC) Training: The next FRC training/Professional Learning Community (PLC) is scheduled for October 18, 2016 from 9:00 a.m.-12:30 p.m. Interested individuals may participate in trainings as space allows. For more information, contact Sue Blount at sue.blount@esd112.org.

State Interagency Coordinating Council (SICC):

The next SICC meeting is July 20 at the Tacoma Mall Plaza Building, 2nd Floor Conference Room, 2702 S 42nd St, Tacoma, 98409. The focus of this meeting is innovative programs. Contact Jahla Brown at (360) 725-4413 or email Jahla.Brown@del.wa.gov for more information or to R.S.V.P.

DSHS, Developmental Disabilities Administration (DDA)
Jamie Bond

Nicole Ferguson attended on behalf of DDA. Nicole provided a handout on Community First Choice (CFC) (see *Attachment #9*). CFC is not a waiver, it's a "state only plan." The benefits and details are listed on the flyer: Personal Care, Caregiver Management Training, Relief Care, Skills Acquisition Training, Assistive Technology, Personal Emergency Response System, and Community Transition Services. Must meet financial eligibility, institutional level of care, and want care in a community setting. There are currently over 13,000 people on this program, and there is no waiting list. For additional information regarding CFC, please contact Nicole Ferguson at nicole.fergason@dshs.wa.gov.

NEW!! The Individual and Family Service Waiver helps support families who have a family member with a developmental disability who is three years or older by providing a choice of services to help maintain and stabilize the family unit. WA State Legislature provided funding for 4,000 new people to receive IFS Waiver services. See *Attachment #10* for current enrollment information while there are still openings.

DSHS, Fostering Well-Being Care Coordination Unit (FWB CCU)
Adam Clarno

Transitioning caseload over to Coordinated Care, almost complete. Not clear on the new role for the Fostering Well-Being program, but still taking calls from social workers and caregivers and working closely with Coordinated Care.

Who is managing children not eligible for foster care managed care (i.e. Native American, some children who are vent-dependent) – or can opt out? HCA says there will be children in foster care not eligible or who can opt out of managed care with Coordinated Care – primarily served through FFS if vent dependent. Those not eligible for Medicaid (non-citizens) – HCA is analyzing this to determine how to serve them, still in the works. Will always be a small group of children in foster care not eligible for managed care and they will be managed by Fostering Well-Being.

DSHS, Kinship and Family Caregiver Program
Hilarie Hauptman
www.dshs.wa.gov/kinshipcare

Hilarie Hauptman was unable to attend. There are no updates at this time.

Lifespan Respite Washington
Linda Porter
www.lifespanrespitewa.org

Linda has received 3 respite applications so far from local health jurisdiction's CSHCN Coordinators for the diagnostic and treatment fund usage pilot that started in late June. Respite vouchers have been awarded to all 3. Linda had a productive meeting with the northern counties in late June, they gave her some suggestions for the Lifespan Respite website, and they found ways to better clarify services with the help of the DOH CSHCN Program team.



WithinReach
Jen St. Cyr
www.withinreachwa.org

Great LINCS (Links to Integrate and Coordinate Services) for CYSHCN (Children and Youth with Special Health Care Needs)

As the Shared Resource for Great LINCS and Washington State's special health care community, Within Reach's Family Health Hotline and ParentHelp123.org began collecting data on families experiencing special health care needs in September of 2015. Since then, WithinReach has worked with many families and providers to connect them to a broad range of resources. In addition to health insurance and food benefits, these resources include complex process navigation such as accessing Applied Behavioral Analysis (ABA) through Medicaid; enrolling in the Developmental Disabilities Administration; engaging with ChildFind through local school districts for special education evaluations and subsequent Individual Education Plans; and troubleshooting the waning of systemic coordination and resources for special health in older youth and young adulthood. The Shared Resource has been carefully created to function as an embedded and sustainable part of the overall Family Health Hotline work, which enables WithinReach to continue collecting important data on connectivity, gaps, and more. As Great LINCS moves forward into year 3, the Shared Resource will continue to improve by optimizing key word search, responding to the needs of care coordinators and families, and further operator training. WithinReach looks forward to opportunities to further collaborate with current and new network partners. If you have input, requests, or questions for the Shared Resource for special health needs and how it can support your work, please contact Jen St.Cyr at WithinReach by email: jennifers@withinreachwa.org, and by phone: 206-830-5173.

Child Development

WithinReach's Child Development Coordinator, Stephanie Orrico, was recently awarded a grant from the Center for Disease Control's *Learn the Signs. Act Early* initiative to support the excellent screening, awareness, and resource work of the Child Development team. Stephanie and the team are thrilled to have the opportunity to increase promotion of this important work as Washington State's LTSAE ambassador.

Immunizations

WithinReach launched the HPV Task Force in 2015, and recently began a new level of coordination among Washington State's immunization network in partnership with the Group Health Foundation. WithinReach will be a connection point for all 16 of the Foundation's HPV initiatives around the State, providing partnership support for a broad range of fields: immunization, cancer prevention, sexual health, and adolescent medicine to name a few. WithinReach is thrilled to support this lifesaving initiative of bringing up HPV vaccination rates across the state with the goal to virtually eliminate morbidity and mortality from cervical cancer.

Summer Meals

It's Summer Meals season! The Washington State Summer Food Service Program (also known as the Summer Meals Program) is one of the federal nutrition programs that provides free breakfast, lunch, and snacks to children and teens 18 and younger during the summer months. Locations include schools, parks, recreation centers, community based organizations, faith based organizations and camps. To locate a site near you, call the Family Food Hotline (1-888-436-6392) or the Family Health Hotline (1-800-322-2588) or use the Summer Meals Search Tool in the ParentHelp123 Resource Finder: <https://resources.parenthelp123.org/services/summer-meals>.

Additional Updates Provided At Communication Network Meeting

Partnering with TANF to connect recipients with THRIVE-coordinated Home Visiting resources – some operators are being trained on this.



THRIVE Washington
Liv Woodstrom
thrivewa.org

Liv Woodstrom was unable to attend. There are no updates at this time.

DOH Screening and Genetics Unit

Deb Lochner Doyle

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

During the 2016 legislative session, House Bill 2403 passed requiring pediatricians and other healthcare providers to share information with parents who receive a pre- or postnatal diagnosis of **Down syndrome**. (<http://app.leg.wa.gov/billinfo/summary.aspx?bill=2403&year=2015>). Lettercase, housed in the National Center for Prenatal and Postnatal Resources at the University of Kentucky, prepared a booklet entitled "Understanding a Down Syndrome Diagnosis." This booklet, printed in English and Spanish, is endorsed by professional and advocacy organizations alike. Therefore, rather than creating new materials, we purchased copies of this booklet to distribute upon request,

Hospitals, Birthing Centers, Obstetricians, Midwives, Pediatricians, Genetic Counselors, Osteopaths, Nurses and Physician Assistants have all been notified that when they have a family whose child is newly diagnosed with Down syndrome, they can request a copy for free through Lettercase (www.lettercase.org) or by emailing us at genetics@doh.wa.gov. This booklet is also available for free online in additional languages such as Korean, Chinese, Japanese, Vietnamese, Somali, Russian, and Spanish: www.understandingdownsyndrome.org.

We also created a list of local organizations in Washington, northern Oregon, and western Idaho that support people with Down syndrome and their families. It can be found at <http://www.doh.wa.gov/genetics>.

New Prenatal Genetic Testing Video Series from Washington State Department of Health (DOH) and Genetic Support Foundation Now Available Online!

Pregnant women are faced with deciding among an increasingly complex variety of prenatal genetic tests. It's essential that they have access to resources that can educate them about these tests.

The Screening and Genetics program collaborated with the Genetic Support Foundation (GSF), to produce a series of seven videos regarding prenatal genetic testing options. The videos are available now on DOH's YouTube Channel (<https://www.youtube.com/user/WADepartmentofHealth>) and are ready to be shared with patients. Here they can select among the series that includes: 1) How to Decide About Prenatal Genetic Testing, 2) Conditions Commonly Tested for During Pregnancy, 3) Prenatal Cell Free DNA Screening, 4) Traditional Maternal Serum Screening, 5) Prenatal Ultrasound, 6) Chorionic Villus Sampling, and 7) Amniocentesis.

These are also posted on our website: (<http://www.doh.wa.gov/prenatalgenetics>) to download.

We hope that both patients and providers will find them useful. Expectant parents can watch at home and health care providers can download them to show patients during office visits.

The storyboard development involved extensive audience testing with the intended audience of women of reproductive age as well as healthcare professionals, parents of children with genetic conditions, and leaders from advocacy groups. Please take a moment to view the videos and consider sharing with colleagues, family and friends. Feel free to share any comments you have at Genetics@doh.wa.gov.

The design for **Universal Developmental Screening Data System** is well underway and includes linking with the Immunization system, so providers have a single sign on to access the system, a child care provider/parent portal as well as a mobile application. Negotiations are ongoing with Brookes about licensing so that they Ages and Stages Questionnaire could be used along with their educational materials. WE are moving into Phase 2 of the design which will involve much greater level of granularity – the details of which data will be collected, what algorithms will be used to calculate age, or when a child is due for a screen, etcetera. If someone wishes to be involved in this work, please contact Deb at Debra.lochnerdoyle@doh.wa.gov.

CSHCN Region – Central

Carol McCormick, Chelan-Douglas County
[The Central Region includes the following counties: Benton-Franklin,
Chelan-Douglas, Grant, Kittitas, Okanogan, Walla Walla, and Yakima]

The Central Region met via conference call June 15th. See *Attachment #11* for the region meeting minutes.
Central Region's next meeting is September 14th via conference call.

CSHCN Regions – East

Melissa Charbonneau, Spokane County
[The East Region includes the following counties: Adams, Asotin, Columbia, Garfield,
Lincoln, NE Tri-County (*Ferry, Pend Oreille, and Stevens*), Spokane, and Whitman]

The East Region met May 12th at Spokane Regional Health District in Spokane. See *Attachment #12* for the region meeting minutes.
East Region's next meeting is August 11th at Spokane Regional Health District in Spokane.

CSHCN Regions, Northwest

Katharine Besch, Seattle-King County
[The Northwest Region includes the following counties: Clallam, Island,
Jefferson, Kitsap, San Juan, Seattle-King, Skagit, Snohomish, and Whatcom]

Additional Updates Provided At Communication Network Meeting

A recent King County voter initiative funded Best Starts for Kids. The Seattle-King Public Health's CSHCN Program does not get extra funding. However, because other public health fund shifts, the CSHCN Program was able to hire 2 .5 FTE nurses for CSHCN help. This will have a positive impact for CSHCN and the whole community.

For more information on Best Starts for Kids, please see

<http://www.kingcounty.gov/elected/executive/constantine/initiatives/best-starts-for-kids.aspx>.

The Northwest Region met June 30th at Snohomish Health District in Everett. See *Attachment #13* for the region meeting minutes.

Northwest Region's next meeting is September 20th at Snohomish Health District Auditorium in Everett.

CSHCN Regions, Southwest

Julie Zambas, Grays Harbor County
[The Southwest Region includes the following counties: Clark, Cowlitz, Grays Harbor,
Klickitat, Lewis, Mason, Pacific, Skamania, Tacoma-Pierce, Thurston, and Wahkiakum]

The Southwest Region met May 26th at Department of Health in Tumwater. See *Attachment #14* for the region meeting minutes.

Southwest Region's next meeting is scheduled for August 25th at Department of Health in Tumwater.

Announcements

- 1. AMCHP Case Study Family Engagement: State Examples.** Family engagement is a critical part of Title V and MCH programs. The Association of Maternal & Child Health Programs (AMCHP) is a national nonprofit organization that supports state and territorial MCH programs and provides national leadership and technical assistance on issues affecting the health of women, infants, children, adolescents and children with special health care needs. Washington is one of three states highlighted in AMCHP's recent publication. (See *Attachment #15*)
- 2. From Amy Huntley at WA Autism Alliance**
We help access ABA as well as other medically necessary autism treatments, community supports, and school supports.

You can either have families call us 425-836-6513 directly, or they can register themselves to become a member (free) and an advocate will reach out to them: <http://www.washingtonautismadvocacy.org/updates/wp-login.php?action=register>.

WAAA also offers free workshops for both families, and community providers on autism insurance benefits, including how to access the right supports, and tips for when people get stuck. For more information, go to <http://www.washingtonautismadvocacy.org/updates/> or call Amy Huntley at 425-836-6513 or amyh@washingtonautismadvocacy.org.

Attachments

1. Healthy Starts and Transitions PowerPoint Slides
2. Flu (Influenza) Fact Sheet
3. Children's Mental Health Community Forum Flyer
4. Update on Blood Lead Screening of Children in Washington State, PowerPoint Slides
5. Lead Screening Recommendations for Children in Washington State
6. Parent to Parent Site Roster, July 2016
7. Transition Trainings Hosted by Parent to Parent
8. Kinderling Center Newsletter
9. Community First Choice Service Options
10. Individual and Family Service Waiver
11. Central CSHCN Region Minutes
12. East CSHCN Region Minutes
13. Northwest CSHCN Region Minutes
14. Southwest CSHCN Region Minutes
15. AMCHP Case Study Family Engagement: State Examples.

Next CSHCN Communication Network Meeting

Thursday, October 13, 2016
Creekside Two at Centerpoint
20425 72nd Avenue South
Kent, Washington
Conference Room 309