CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM

COMMUNICATION NETWORK MEETING

January 12, 2017

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.

<table>
<thead>
<tr>
<th>Attendee</th>
<th>Phone Number</th>
<th>Email Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kevin Cornell, Health Care Authority (unable to attend)</td>
<td>360-725-1423</td>
<td><a href="mailto:kevin.cornell@hca.wa.gov">kevin.cornell@hca.wa.gov</a></td>
</tr>
<tr>
<td>Colette Jones, Health Care Authority</td>
<td>360-725-1782</td>
<td><a href="mailto:colette.jones@hca.wa.gov">colette.jones@hca.wa.gov</a></td>
</tr>
<tr>
<td>Adam Clarno, Health Care Authority (unable to attend)</td>
<td>360-725-0731</td>
<td><a href="mailto:adam.clarno@hca.wa.gov">adam.clarno@hca.wa.gov</a></td>
</tr>
<tr>
<td>Cary Robertson, Amerigroup-Washington (unable to attend)</td>
<td>206-695-7081, ext. 54552</td>
<td><a href="mailto:Cary.Robertson@amerigroup.com">Cary.Robertson@amerigroup.com</a></td>
</tr>
<tr>
<td>Melissa Shilipetar, Community Health Plan of Washington (unable to attend)</td>
<td>206-613-5086</td>
<td><a href="mailto:melissa.shilipetar@chpw.org">melissa.shilipetar@chpw.org</a></td>
</tr>
<tr>
<td>Elizabeth Allen, Coordinated Care</td>
<td>253-442-1428</td>
<td><a href="mailto:ELALLEN@coordinatedcarehealth.com">ELALLEN@coordinatedcarehealth.com</a></td>
</tr>
<tr>
<td>Sherry Bennatts, Coordinated Care</td>
<td>253-442-1543</td>
<td><a href="mailto:sbennatts@coordinatedcarehealth.com">sbennatts@coordinatedcarehealth.com</a></td>
</tr>
<tr>
<td>Christy Schneck, Coordinated Care</td>
<td></td>
<td><a href="mailto:CSCHNECK@coordinatedcarehealth.com">CSCHNECK@coordinatedcarehealth.com</a></td>
</tr>
<tr>
<td>Cathi Sears, Molina Healthcare of Washington (unable to attend)</td>
<td>800-869-7175, ext. 147148</td>
<td>catherine.sears@molinah ealthcare.com</td>
</tr>
<tr>
<td>Cindy Spain, United Healthcare (unable to attend)</td>
<td>206-749-4347</td>
<td><a href="mailto:cindy_i_span@uhc.com">cindy_i_span@uhc.com</a></td>
</tr>
<tr>
<td>Jacquie Stock, CCSN at Seattle Children’s (unable to attend)</td>
<td>206-987-3729</td>
<td><a href="mailto:jacquie.stock@seattlechildrens.org">jacquie.stock@seattlechildrens.org</a></td>
</tr>
<tr>
<td>Kate Orville, Medical Home Partnerships for CYSHCN (unable to attend)</td>
<td>206-685-1279</td>
<td><a href="mailto:orville@uw.edu">orville@uw.edu</a></td>
</tr>
<tr>
<td>Amy Carlsen, Medical Home Partnerships for CYSHCN</td>
<td>206-685-1293</td>
<td><a href="mailto:carlsa@uw.edu">carlsa@uw.edu</a></td>
</tr>
<tr>
<td>Sharon Feucht, University of Washington, Nutrition Program (unable to attend)</td>
<td>206-685-1297</td>
<td><a href="mailto:sfeucht@uw.edu">sfeucht@uw.edu</a></td>
</tr>
<tr>
<td>Louis Mendoza, Washington State Fathers Network (unable to attend)</td>
<td>425-747-4004, ext. 4286</td>
<td><a href="mailto:louis.mendoza@kindering.org">louis.mendoza@kindering.org</a></td>
</tr>
<tr>
<td>Susan Atkins, WA State Parent to Parent (unable to attend)</td>
<td>1-800-821-5927</td>
<td><a href="mailto:parent2parentwa@gmail.com">parent2parentwa@gmail.com</a></td>
</tr>
<tr>
<td>Jill McCormick, Family to Family Health Information Center</td>
<td>253-565-2266</td>
<td><a href="mailto:jmccormick@wapave.org">jmccormick@wapave.org</a></td>
</tr>
<tr>
<td>Ginger Kwan, Open Doors for Multicultural Families (unable to attend)</td>
<td>253-216-4479</td>
<td><a href="mailto:gingerk@multiculturalfamilies.org">gingerk@multiculturalfamilies.org</a></td>
</tr>
<tr>
<td>Robin Fleming, Office of Superintendent of Public Instruction</td>
<td>360-725-6050</td>
<td><a href="mailto:robin.fleming@k12.wa.us">robin.fleming@k12.wa.us</a></td>
</tr>
<tr>
<td>Marianne Bastin, Good Samaritan Hospital, Children’s Therapy Unit, Neurodevelopmental Centers Representative</td>
<td>253-697-5200</td>
<td><a href="mailto:marianne.bastin@multicare.org">marianne.bastin@multicare.org</a></td>
</tr>
<tr>
<td>Debi Donelan, DEL, Early Support for Infants and Toddlers (ESIT) (unable to attend)</td>
<td>360-725-4400, 360-725-3519</td>
<td><a href="mailto:debra.donelan@del.wa.gov">debra.donelan@del.wa.gov</a>, <a href="mailto:kathryn.grant-davis@del.wa.gov">kathryn.grant-davis@del.wa.gov</a></td>
</tr>
<tr>
<td>Nicole Fergason, DSHS, Developmental Disabilities Administration (unable to attend)</td>
<td>360-725-3525</td>
<td><a href="mailto:nicole.fergason@dshs.wa.gov">nicole.fergason@dshs.wa.gov</a></td>
</tr>
<tr>
<td>Michelle Milholland-Fears, DSHS, Aging and Long-Term Support Administration, Fostering Well-Being Care Coordination Unit (unable to attend)</td>
<td>360-725-3801</td>
<td><a href="mailto:michelle.milholland-fears@dshs.wa.gov">michelle.milholland-fears@dshs.wa.gov</a></td>
</tr>
<tr>
<td>Hilarie Hauptman, DSHS, Kinship and Family Caregiver Program</td>
<td>360-725-2556</td>
<td><a href="mailto:hilarie.hauptman@dshs.wa.gov">hilarie.hauptman@dshs.wa.gov</a></td>
</tr>
<tr>
<td>Linda Porter, Lifespan Respite Washington (unable to attend)</td>
<td>425-740-3788</td>
<td><a href="mailto:lporter@sssc.org">lporter@sssc.org</a></td>
</tr>
<tr>
<td>Jen St. Cyr, WithinReach</td>
<td>206-830-5173</td>
<td><a href="mailto:jenifers@withinreachwa.gov">jenifers@withinreachwa.gov</a></td>
</tr>
<tr>
<td>Liv Woodstrom, THRIVE Washington (unable to attend)</td>
<td>206-621-5571</td>
<td><a href="mailto:liv@thrivewa.org">liv@thrivewa.org</a></td>
</tr>
<tr>
<td>Deb Lochner Doyle, DOH/Screening and Genetics Unit (unable to attend)</td>
<td>253-395-6742</td>
<td><a href="mailto:debra.lochnerdoyle@doh.wa.gov">debra.lochnerdoyle@doh.wa.gov</a></td>
</tr>
<tr>
<td>Nini Shridhar, DOH/Screening and Genetics Unit</td>
<td>253-395-6743</td>
<td><a href="mailto:nirupama.shridhar@doh.wa.gov">nirupama.shridhar@doh.wa.gov</a></td>
</tr>
<tr>
<td>Katharine Besch, Northwest CSHCN Region Co-Representative</td>
<td>206-263-1244</td>
<td><a href="mailto:katharine.besch@kingcounty.gov">katharine.besch@kingcounty.gov</a></td>
</tr>
<tr>
<td>Julie Zambas, Southwest CSHCN Region Representative</td>
<td>360-500-4051</td>
<td><a href="mailto:jzambas@co.grays-harbor.wa.us">jzambas@co.grays-harbor.wa.us</a></td>
</tr>
<tr>
<td>Carol McCormick, Central CSHCN Region Representative</td>
<td>509-886-6423</td>
<td><a href="mailto:Carol.Mccormick@cshcnregion.org">Carol.Mccormick@cshcnregion.org</a></td>
</tr>
<tr>
<td>Melissa Charbonneau, East CSHCN Region Rotating Representative</td>
<td>509-324-1665</td>
<td><a href="mailto:mcharbonneau@cschnregion.org">mcharbonneau@cschnregion.org</a></td>
</tr>
<tr>
<td>Maria Nardella, Healthy Starts &amp; Transition Unit</td>
<td>360-236-3573</td>
<td><a href="mailto:maria.nardella@doh.wa.gov">maria.nardella@doh.wa.gov</a></td>
</tr>
<tr>
<td>Christy Polking, Healthy Starts &amp; Transitions Unit</td>
<td>360-236-3571</td>
<td><a href="mailto:christy.polking@doh.wa.gov">christy.polking@doh.wa.gov</a></td>
</tr>
</tbody>
</table>
CSHCN Program Updates

Flu: There is currently a serious flu outbreak in WA. As a reminder, DOH has updated the Flu Fact Sheet for children with special health care needs to reflect the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices (ACIP) 2016 guidelines. The fact sheet is available in English, Russian, Spanish, and Vietnamese.

Below are the new links on the H.E.R.E. website:
HERE record: http://here.doh.wa.gov/materials/flu-influenza
Russian PDF: http://here.doh.wa.gov/materials/flu-influenza/13_FluSpecial_R16L.pdf
Spanish PDF: http://here.doh.wa.gov/materials/flu-influenza/13_FluSpecial_S16L.pdf
Vietnamese PDF: http://here.doh.wa.gov/materials/flu-influenza/13_FluSpecial_V16L.pdf

Staff Updates: Healthy Starts & Transitions (See Attachment #1 for PowerPoint presentation.) The Healthy Starts and Transitions (HST) Unit, Children with Special Health Care Needs Program is pleased to announce our newest team member, Jean-Marie Dymond. Jean-Marie will be coordinating our Autism and other Developmental Disabilities ("AS3D") grant. Jean-Marie’s previous experience includes working at HCA in Medical Eligibility, and was an entrepreneur. She also worked for North Thurston Public Schools as a special education para-educator for young children with autism and other developmental disabilities and so brings direct experience and a strong passion to achieve the goals of the AS3D grant! Her email address is jean-marie.dymond@doh.wa.gov. Also, Shauna Muendel left HST Child Health and Development Program to work in another program at DOH—she will be Nurse Consultant/Data Manager for the Breast, Cervical and Colon Health Program; we will recruit for a replacement soon. In the interim, contact Leslie Carroll (leslie.carroll@doh.wa.gov). As shared at the last CommNet meeting in October 2016, Christine Stalie, former ECCS Coordinator with HST Child Health and Development program, has left to join DOH’s TCPI team as the Practice Facilitator for Seattle/King County. We wish both Shauna and Christine well in their new endeavors!

AS3D (Autism and Other Developmental Disabilities) Grant: As mentioned above, we are very excited to have our new grant coordinator, Jean-Marie Dymond, on board! Progress on the infrastructure of the grant is being made—our coordinator is hired and getting oriented, our three new contracts with family-led organizations (Washington Autism Alliance and Advocacy, Open Doors for Multicultural Families, and Northwest Autism Center) are being finalized, and we had our kickoff web-meeting of the AS3D Project Advisory Committee in November 2016. The webinar introduces DOH’s new Autism/Other Developmental Disabilities ("AS3D") Grant to key external grant partners, who will be members of the AS3D Project Advisory Committee. Content includes a review of the grant goals, objectives, and work plan; as well as a review and discussion of the roles and responsibilities of the Project Advisory Committee. Recording time is 1 hour 15 minutes. If you have time and are interested, we welcome you to watch the recording here: https://youtu.be/3o91BfVXiUE).

For more information, please contact Meredith Pyle at 360-236-3536 or Meredith.pyle@doh.wa.gov

CSHCN Program/Nutrition Background and Updates: Background: Children with special health care needs (CSHCN) are at increased risk for nutrition, growth and feeding problems. It has been estimated that up to 40% of CSHCN have nutrition risk factors that could be helped by a referral to a registered dietitian (RDN) and the risk may be even higher in certain subgroups. In Washington State up to 15% of children have special health care needs. Access to services is a frequently identified problem for families of CSHCN. Washington State began to address the issue of access to nutrition

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services for CSHCN through a nutrition contract with UW in 1983. Through contract activities, between 1983-1987 a need to expand workforce capacity through training for RDs seeing CSHCN was identified. In 1986-1987 a 5 day training was conducted at 7 identified sites across the state. RDs at these sites expressed the need for ongoing skill development. In 1987 a 3 day training for RDs seeing CSHCN (8 RD attendees) formed the basis for the Statewide Nutrition Network. Through continued contract activities, DOH has supported training, CE opportunities, and networking, expanding the number of Nutrition Network Members to 200. These Network Members are located across the state in all but 4 counties.

Needs Assessment: DOH, in partnership with the UW State Nutrition contract is now conducting a statewide nutrition needs assessment to include mapping of needs as well as resources. To date, we have mapped the estimated population of CSHCN by county, the location of network and WIC clinics by county, and are finalizing a survey tool which will be sent to Network members and WIC clinics in early February. Next steps are to identify provider and parent groups for informed interviews focused on group needs and experiences. If you are interested in participating as a provider or parent, or know of anyone who would be interested, please contact Joan Zerzan at joan.zerzan@doh.wa.gov. Feeding Supports and Transition from Hospital to Home Workgroup: (see Attachment 1 slides).

Partner Announcement: Registration for Assuring Pediatric Nutrition in the Hospital and Community is now open. This conference provides up-to-date, evidence-based pediatric nutrition information for RDs. This training is an excellent addition to the RD's Professional Development Portfolio and can be used to help document the dietitian's competencies with children of different ages as required by JCAHO. At the end of the conference, participants will become members of an on-going Pediatric Nutrition Consultation On-Line listserve. Summary information is below, and additional information (including brochure & registration materials) are available online: http://depts.washington.edu/nutrpeds/ce/3day.html

May 9-11 and May 11-12, 2017
Talaris Conference Center
Seattle, Washington

New this year – expanded format
In addition to our traditional 3-day conference, we are holding a 2-day option with advanced content

Option 1 (May 9-11, 2017)
Our “traditional” 3-day conference that is intended for RDNs and other professionals who work with pediatric populations and have not had extensive or recent training and experience in pediatric nutrition

Option 2 (May 11-12, 2017)
This 2-day option is intended for RDNs who have attended a previous Assuring Pediatric Nutrition conference or who have a solid foundation in pediatric nutrition. Several topics will be addressed in-depth, with a combination of didactic (lecture) and active learning.

Option 3 (May 9-12, 2017)
This “best value” option combines Options 1 and 2 – stay 4 days and hear it all

Registration is limited to facilitate interactive, small group learning experiences and to promote the development of clinical competencies. For more information or to receive registration details when they are available, contact Beth at bogata@uw.edu. Sponsored by University of Washington, Center on Human Development and Disability and Seattle Children's Hospital

2017 Legislative Session: The Washington State Legislature (http://leg.wa.gov/) 2017 Legislative Session is scheduled for from January 9 through April 23, 2017. The governor's proposed budget was released in December 2016. Part of the governor’s budget proposal includes a reduction in funding (about $40,000/year less per NDC per year) in funding to the neurodevelopmental centers throughout the state. This equates to a $1.3 million hit to the state's early intervention system. A summary of the proposal as it would impact DOH can be found here: http://www.ofm.wa.gov/budget17/recsum/303.pdf. WA Chapter of AAP released a legislative agenda for 2017: http://wcaap.org/advocacy/active-issues/. Themes include access to care (increase pediatric Medicaid reimbursement to Medicare rates; improve access to appropriate behavioral health care for children), give children a healthy start (invest in evidence-based early childhood programs; provide paid family and medical leave), and keep children safe (reduce distracted driving; decrease child firearm injuries; raise the legal age to purchase tobacco products to 21). Visit the Arc of WA's Legislative Action Center: http://capwiz.com/arcwa/state/main/?state=WA and check out their 2017 Legislative Notebook: http://arcwa.org/index.php/takeaction/washingtonstate/issue_papers/2017_legislative_notebook/.

Affordable Care Act: There are two new resources available regarding Washington State and the positive impact of the Affordable Care Act (ACA). See Attachment #2 for “The Affordable Care Act Post 2016: What’s at Stake for Washington State?” fact sheet and Attachment #3 for the PowerPoint slides.
Northwest Rural Health Conference: The 2017 Northwest Rural Health Conference is approaching! This year’s theme is: Meeting the Challenge: Caring for Rural Communities Together. It's scheduled from February 27 – March 1, 2017 at the DoubleTree by Hilton SeaTac Airport. Scheduling details are as follows: Monday, February 27: Intensive Learning Labs; Tuesday-Wednesday, February 28-March 1: Conference Sessions and Exhibits. Registration is open at [http://depts.washington.edu/uwconf/wordpress/nwrhc/registration/](http://depts.washington.edu/uwconf/wordpress/nwrhc/registration/). In 2017 the conference will take place on the west side of the state – starting a new tradition of rotating east to west annually. The conference will be back to the east side in 2018. Organizers understand this disrupts a long-held tradition – they hope this rotation enables our rural health systems on the west side to more easily attend the conference.

Sound Transit light rail is steps away and easy to use – visit Seattle after the sessions to dine or sightsee. The Northwest Rural Health Conference addresses varied facets of providing health care in rural settings including critical access hospitals, rural emergency medical services, rural health clinics, home health and other health organizations.

Washington State Leadership Initiative—We had a statewide leadership meeting on November 9th. We had 2 sites and teleconferenced them together. We had speakers in both Spokane and in Kent. Topics discussed were advocacy and leadership development opportunities at the National Level, with Darci Ladwig presenting on an internship with Arc USA; Collective Impact tools to increase collaboration-presented by Jen St Cyr; and Leadership development in diverse families, a panel presentation from the Arc of King County. Our WSLI SharePoint site has been up and running since September and now has 48 external partners across the state connected! We receive a lot of positive feedback about the tools and resources available on the site to facilitate statewide collaboration. I have been working with Arc of Whatcom County and we will be developing a webinar to outreach to multiple stakeholders around continuing the work of ensuring that doctors are aware of materials available on the DOH resources site for women with a prenatal diagnosis of Down Syndrome. The webinar is planned for early February-stay tuned! The program evaluation group is working on a logic model around statewide family engagement, and the steering committee is learning to use some systems mapping tools at our next meeting, which will be facilitated by Jen St Cyr. Our state agency workgroup consists of many state agency reps who are working on assessing and expanding family engagement opportunities within their agencies. A number of family advisor opportunities have been identified and are available on SharePoint.

For more information, contact Michelle Hoffman, Family Engagement Coordinator michelle.hoffman@doh.wa.gov

DOH Budget Update

The changing federal government landscape post elections has people wondering about the possible impacts to the Department of Health and our state. A change in administration at the federal level may cause impacts to state agency budgets through the federal grants and new policy directions. At this time, there is no specific information on these types of impacts. We assume we will begin to learn more as the new year unfolds when the new administration takes over and implements budget and policy decisions.

- In a recent Results WA meeting, the Governor was clear that he will continue to work hard to assure access to health insurance, fund education, support kids and prevent climate change.
- DOH is pulling together a full list of programs that are supported with federal dollars to have a very current comprehensive picture of portfolio of federal funding.
- DOH is working with the Governor’s office to provide an overview of federal grant work and budgets. This includes ensuring the Governor’s Federal Liaison is knowledgeable about specific impacts and concerns.
- With any administration change there are opportunities and challenges. DOH will actively look to identify possible challenges as well as find opportunities to build on its work.

Pediatric-Transforming Clinical Practice Initiative (P-TCPI) – see Maria Nardella’s PowerPoint slides attachment. The Washington State Department of Health (DOH) was awarded the Pediatric-Transforming Clinical Practice Initiative grant (P-TCPI) in September 2015 from the Center for Medicaid and Medicare Services (CMS). P-TCPI is a 16.3 million dollar grant that aims to transform pediatric care for 350,000 children (0-20 years of age) in Washington State over 4 years. To achieve this, DOH is working in partnership with the Washington Chapter of the American Academy of Pediatrics (WCAAP), Molina, Child and Adolescent Clinic, and a network goal of 5,600 clinicians to improve outcome measures for children through family-centered, high quality and cost effective care.

The P-TCPI grant is being implemented regionally using the nine Accountable Communities of Health (ACH) regions. Each ACH region includes a P-TCPI regional grant team with a Practice Facilitator employed by DOH, a physician champion, a behavioral health champion, and a Molina representative to represent their region with the ACHs and work together to integrate health systems regionally and statewide for children. Through a new Regional Care Coordination Project, the P-TCPI grant hopes to now add a Regional Care Facilitator to these teams, one for each of the nine ACHs, to bring a pediatric care coordination and a family resource lens to this project.

The Regional Care Facilitator will build relationships and bridges between pediatric care coordinators from all sectors of their community, enhance the medical home neighborhood model of care, create a regional network of pediatric care
coordinators and emphasize physical and behavioral health integration and care coordination. The ideal candidates for this role will be trained and familiar with pediatric care coordination, familiar with local and regional efforts to improve the wellbeing of children and youth, well-versed in population health, and familiar with pediatric systems of care. DOH hopes to reach out to the existing local health jurisdiction (LHJ) Children with Special Health Care Needs (CSHCN) Care Coordinators to fill this role.

DOH will release an announcement letter to the LHJs asking to identify a single CSHCN Coordinator from their region who would be interested in representing their ACH region and filling this role. The participating LHJ will be compensated approximately $81,800 dollars per year to cover .75FTE and regional travel. The other .25 FTE would continue to be spent working in their usual host LHJ with children and families. The current proposed timeline for the Regional Care Coordination Project includes consolidated contract amendments in February or March with work beginning in March or April. This project will continue until the end of the P-TCPI grant on September 29, 2019.

For more information, please contact Maria Nardella at 360-236-3573 or maria.nardella@doh.wa.gov.

Essentials for Childhood (EfC)

Steering Committee Leadership

David Bley, Director Bill & Melinda Gates Foundation Pacific Northwest Initiative, and Dr. Nancy Anderson, Bastyr University, have joined Secretary of Health John Wiesman as Co-Chairs of the EfC Steering Committee. This transition is critical to making the EfC Steering Committee the venue where state leaders from community, philanthropy and government collaborate to assure all children in Washington State thrive in safe, stable and nurturing relationships and environments. We are strengthening initiative processes and structures to clarify roles, expectations and plans.

Essentials Workgroups

- Community & Stakeholder Education & Action is working to create a statewide learning and community of practice/systems infrastructure for those doing the work to connect, share and gain resources, and be highlighted to and connected with state and system leaders, philanthropy, and public policy makers.

- Systems, Services & Implementation workgroup has chosen Help Me Grow as the framework for addressing its charges to align systems to enable family-centered serve provision and transform systems and services to prevent and mitigate the impacts of trauma. They are learning from communities about successes and barriers implementing Help Me Grow and expect to bubble up common issues to identify state policy implications. Issues that they are seeing so far include: workforce challenges, how to do a “warm handoff” of clients between organizations, data management across communities, and creating a learning environment for Help Me Grow Communities.

- Innovative New Policy & Financing Whole Child subgroup has proposed recommendations for policy changes and increasing K-12 school staff positions in support of social and emotional health and learning of students. These recommendations are consistent with the Governor’s education plan (2017-2019) and the October 2016 legislative report of the OSPI Social Emotional Learning Benchmarks workgroup.

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

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

Great LINCS is currently in its final 7 months. The remaining part of the grant will focus on promoting the shared resource and sharing the project activities with partners. There will also be a focus on sustainability by integrating some of the goals of Great LINCS into TCPI medical home goals.

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

Great MINDS Project Updates

Great MINDS has a scheduled upcoming training for the Benton Franklin region in Richland on January 20th, 2017. WCAAP will continue to schedule trainings. WCAAP will also be working with the DOH autism grant to create Great MINDS plus Autism trainings. This is expected to be available late summer 2017.

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

Project LAUNCH Expansion

Project LAUNCH (PL) submitted the first year report to SAMHSA. Evaluation plan was submitted at the end of October. SAMHSA just returned the evaluation plan with questions. PL will update and return to SAMHSA. With Element 1 in full swing, PL is beginning to develop Element 2, Mental Health Consultation in partnership with Department of Early Learning (DEL) and Washington State Association for Infant Mental Health (WA-AIMH). The state and local lead had several meetings with DEL and WA-AIMH to develop a process for providers to apply and go through the endorsement pathway to be endorsed at a level 1 or 2. These meetings will continue as we develop tools that will provide insights to providers and professionals alike on the Endorsement® pathway, which will include benefits of the Infant Mental Health endorsement competency guidelines as well as more clear and concise information about the Endorsement® pathway.
year 2 PL will also partner with WithinReach to support a growing demand for resource and referral services from the enhanced implementation of developmental and social-emotional screening, to include the Devereux Early Childhood Assessment (DECA) and Parent Stress Index (PSI) in the three pilot communities.

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

**Universal Developmental Screening (UDS)**

On December 15, 2016, members of the Help Me Grow-Washington (HMG-WA) Partnership convened at the Green River College in Auburn to plan for the future of the partnership’s work related to increasing rates of developmental screening and expanding the HMG model statewide. Following a day-long discussion, the participants developed the following recommendations:

1. Disband the current HMG-WA Partnership structure.
2. Transfer support for HMG efforts to Essentials for Childhood’s (EfC) Systems, Services, and Implementation Workgroup. This partnership can “test the waters” of merging or moving our mission forward in this way and make a decision in the future about whether or not this is adequately meeting the need.
3. Potentially form a new cross-agency partnership focused on alignment of efforts to promote healthy child development (including development of a message map for multiple audiences such as providers, families, legislators, etc.).
4. Hold conferences or meetings of partners doing and excited about work focused on promoting healthy development as an opportunity for them to share their best practices with each other.

Next steps discussed included

1. Communication with EfC Systems, Services, and Implementation Workgroup co-chairs about HMG-WA/P partner interest in participation in this workgroup.
2. Identification of an “organizing entity” for the cross-agency alignment partnership. This group would make decisions about its purpose and functions (e.g., communication platform, leadership structure, message map, pursuit of funding, etc.).
3. Dissemination of a survey to partnership members to determine interest in annual meetings.

Further effort is needed to identify participants interested in taking responsibility for these next steps, to develop a summary of the status of the work of the partnership’s action teams, and to determine where that work could be continued.

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

**Healthy Communities Consolidated Contracts Updates**

Four regional meetings were held in October with a total of 52 local attendees including MCH leads, program staff and administrators. Topics for the regional meetings included foundational public health services, Accountable Communities of Health, the changing MCH work force, and discussion of local strategies around Children with Special Health Care Needs, Universal Developmental Screening (UDS), and Adverse Childhood Experiences (ACEs).

During 2017, the Washington State Department of Health (DOH) is hosting six topical calls from January through June for local MCH contractors and partners. All calls are scheduled at 9am on the first Thursday of the month. The first will be held on January 5 and the topic is Culturally Appropriate Adolescent Health Care, with Rabeeha Ghaffar and Cynthia Morrison of DOH. Subject matter for future calls will include:

- Beyond ACEs: Adverse Community Events
- Accountable Communities of Health: future engagement strategies
- MCH Workforce: Moving toward Policy, Systems and Environmental (PSE) approaches
- Early Support for Infants & Toddlers, UDS and other statewide tools/programs
- Foundational Public Health Services & Maternal and Child Health

*For more information, please contact Chris Zipperer at 360-236-3614 or chris.zipperer@doh.wa.gov.*
The Northwest Region met October 26th at Island County Public Health in Coupeville. See Attachment #4 for the region meeting minutes.
Northwest Region Meeting schedule for 2017: March 30th (Island County Public Health, Coupeville), June 29th (Snohomish Health District, Everett), September 28th (Skagit County Public Health, Coupeville), and December 14th (telephone conference call).

The Southwest Region met November 17th at Department of Health in Tumwater. See Attachment #5 for the region meeting minutes.
Southwest Region Meeting schedule for 2017: February 23rd (via conference call), May 25th, August 24th, and November 16th (all in-person meetings in Tumwater).

The Central Region met via conference call December 14th. See Attachment #6 for the region meeting minutes.
Central Region Meeting schedule for 2017: March 22nd, June 21st, and September 20th all via telephone conference call.

The East Region met November 10th at Spokane Regional Health District in Spokane. See Attachment #7 for the region meeting minutes.
East Region Meeting schedule for 2017: January 12th (in conjunction with Communication Network via video conference), May 11th, August 10th, and November 9th (all in person meetings in Spokane).

Special Presentation
Pediatric – Transforming Clinical Practices (TCPI) Overview
Maria Nardella, Healthy Starts and Transitions Unit Manager

See Attachment #8 for PowerPoint slides and pages 4-5 of the minutes for additional information regarding the P-TCPI grant.

- HCA signed an agreement with the Centers for Medicare and Medicaid Services (CMS) for a five-year Medicaid transformation demonstration waiver. This will provide up to $1.1 billion in incentives for our health system providers to achieve better health, better care, and better value. In addition, $375 million is provided to support critical wrap-around services for Apple Health (Medicaid) clients. Learn more through this short (7min) video: http://hca.wa.gov/about-hca/healthier-washington/medicaid-transformation
- Expansion of the Health Home program in King and Snohomish beginning April 1, 2017
• Integration work continues: We are working towards 2020 when we are required to have fully integrated managed care contracting across the entire state. Integration includes physical and behavioral health (mental health and chemical dependency). Southwest Washington (Clark and Skamania) were the first region integrated and North Central will be the next. North Central (Grant, Chelan, and Douglas Counties) will be integrated in 2018.
• Medicaid as secondary receive Medicaid through a Medicaid MCO as of 1/1/2017; MCO is the agency responsible for coordination of benefits (about 30,000 clients statewide);
• If folks have questions/issues (eligibility, benefits, etc.), please try to be as specific as possible by including the name and ProviderOne ID if available and a discussion of the issue.
• Children’s survey: In early 2017, a survey will be done to see how children and children with chronic conditions are served in Medicaid Managed Care (called Consumer Assessment of Healthcare Providers and Systems/CAHPS).

How can a Medicaid client change managed care plans?
To change your health plan:
  • Go to www.wahealthplanfinder.org
    This option is available for clients with a HealthPlanFinder account.

These options are available to all Apple Health clients:
• Visit the ProviderOne Client Portal website https://www.waproducerone.org/client
• Call Apple Health Customer Service at 1-800-562-3022. Our automated system is available 24 hours a day, 7 days a week.
• Request a change online at https://fortress.wa.gov/hca/p1contactus/client_webform/
  Select the topic “Enroll/Change Health Plans.”

If you have questions, call toll-free at 1-800-562-3022 (711 for relay services).

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<th>Cary Robertson</th>
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Cary Robertson was unable to attend.

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Melissa Shilipetar was unable to attend.

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• Coordinated care is working on our accreditation with NCQA (National Committee for Quality Assurance).
• Coordinated Care’s quality team is part of the MCO well child PIP workgroup as well as the Disparity Racial/Ethnic Analysis Workgroup collaboration with DOH.
• Elizaboth will be attending the Association of Maternal Child Health Programs (AMCHP) conference in March.
• 23,000 members; Care Coordination to 20,000 members; Foster care – 9 months; new programs since go live; A to A program (Adolescent transitions); help with resources;
• TEAM Monitor
• Molina is hiring a new case manager to be embedded at Seattle Children’s.
• A new nurse will be starting in April to focus on identifying children with special health care needs.
• Cathi transitioning back into care coordination; continues to assist with autism and ABA benefits.

Cindy Spain was unable to attend.

• CCSN’s Web Coordinator is nearing end of a complete website overhaul. Not a simple remodel/flip job but a complete rebuild from the foundation up. Before starting the project, our Web Coordinator used Google Analytics’ data to structure the new site around our current website’s 25 most popular web pages. Working with the Center’s Senior Health Educator, they then created a website navigation that flowed and followed the typical steps from Diagnosis to Adolescent Transition. A few of the new features of the refreshed website include a revamped Summer Camp directory that always delivers positive results, community calendar of statewide events, a rooted connection to social media/sharing and site navigation that is more intuitive. **The new site is designed for mobile with phone/tablet browser specific resources.**
• The CCSN is participating in the Medical Home Neighborhood portion of the Transforming Clinical Practice Initiatives grant to assure parent and provider resources and information from the Center are available throughout the State and region.
• The Center’s Nurse Consultant worked with Seattle Children’s asthma care providers, care coordinators, school nurses and other partners to develop smooth care coordination between Seattle Children’s and community providers and settings for children with asthma.
• CCSN is actively reaching out to the managed care organizations to identify training needs and resources for covered members. Please contact Jacquie to participate.
• Care Coordination should be embedded into all our work: one outcome of the Transition and Longitudinal Care (TLC) group is that care coordinators need to work together – whether in a facility or in the community.

Lots of exciting activities going on! Here’s are some of the highlights:

**New LEND/Medical Home Community Collaboration and Advocacy Skills Curriculum - “Adopt a County”**
• MHPP staff partnered with UW Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Faculty this quarter to develop a pilot 5-week experiential curriculum on effective advocacy through community collaboration and mobilization. We identified 10 communities we’d worked with and had Fellows learn about either Autism, Universal Developmental Screening (UDS), Adverse Childhood (ACES) or Hearing Screening needs and efforts in these communities. LEND/MHPP staff identified data sources and developed worksheets for Fellows to research and
evaluate county and state demographic data online. We gave presentations and technical assistance to the LEND teams on working with communities around Autism (Amy), ACES (Kate) and UDS (Kathy TeKolste/Sue Wendel-LEND). The teams developed brief needs assessment presentations and proposed policy statements.

- LEND fellows overwhelmingly reported that the most valuable and exciting part of the process was their interviews with local key informants. As a result of the project, one community RD Fellow on the Chelan-Douglas team is continuing to participate with the local Autism Coalition and other efforts and two Fellows are attending an ACES training in Kitsap County. We are encouraging Fellows to come to us with ideas for community-based LEND Leadership projects and will build an even more direct link to this outcome next year. Thank you partners in Benton-Franklin, Kitsap and Yakima (ACES), Chelan-Douglas, Lewis, Skagit and Whatcom (Autism), Snohomish, Spokane (UDS), and King (Hearing Screening)!


### Autism-related Technical Assistance to Communities Growing Local ASD Evaluation and Intervention services

- MHPP is helping with the DOH AS3D Autism grant. Kate was privileged to go to the kickoff meeting in DC with other partners from DOH, WA Autism Alliance and Advocacy, NW Autism Center, Open Doors for Multicultural Families.

- **Grant County Medical Home Leadership Network (MHLN) team**- The pediatrician from local ASD Center of Excellence contacted MHPP for assistance finding legal advice in how the community could add intervention services to the mix of diagnostic services. We were able to connect her to WAAA for legal advice and to partners at NW Autism Center, Yakima and Seattle Children’s for support developing an intensive early intervention ABA program.

- **The Whatcom County MHLN team** requested training and technical assistance for a pediatrician who is stepping up to do more ASD diagnostic work locally. We were also able to connect them with the growing group of communities and TA for intensive early intervention ABA program.

- **Collaboration with Chelan-Douglas LHJ and Early Learning leaders and the CD Autism Coalition** – Amy and Kate met with monthly Autism Coalition in November to discuss CAM and whether the group wanted to use CAM to help them move forward. The coalition voted unanimously to move forward. Amy and Kate are helping group leaders with pre-work on existing community assets and gaps before a bigger kickoff with community leaders later this year.

### Universal Developmental Screening and connecting families to needed services.

- We participated in the DOH-sponsored October 17 meeting “Improving Access to Developmental and Behavioral Screening, Assessment, Referrals and Services: Multiple Models.” Amy and Kate recruited and collaborated on panel presentation October 17 with leaders from Spokane and Snohomish County CAM Coalitions. [Spokane](http://www.hca.wa.gov/about-hca/healthier-washington/practice-transformation-support-hub) and [Snohomish](http://www.hca.wa.gov/about-hca/healthier-washington/practice-transformation-support-hub) Counties shared their experiences and innovative ideas for promoting and sustaining Universal Developmental Screening within their communities. Agenda and PowerPoint Presentation.

- **Developmental screening in the medical home for immigrant and refugee families.** Kathy, Kate and Amy participate in a multi-agency workgroup that provides technical assistance to Medical Director Abby Grant and other staff from Harborview Pediatrics in Seattle as they implement developmental screening for all their diverse families. The clinic has switched from the Ages and Stages Questionnaire (ASQ) to the public domain Survey of Wellbeing of Young Children (SWYC) under development by Tufts University. Harborview is working with Somali staff and local leaders to translate the tool into Somali for a pilot this year. So far, the staff and 12 pediatric residents using the tool are very positive about the SWYC and are tracking data about its use. UW researcher Julie Kientz and colleagues are collaborating with ideas for using technology to improve screening. King County Early Intervention and WithinReach are also participating and helping the Harborview medical home learn about what community services are available and how best to connect families.

### Connection with Health Transformation Activities

- **Pediatric-Transforming Clinical Practice Initiative (P-TCPI)** – Kate, Amy and Kathy are participating in the Medical Home neighborhood committee and helping define the work of this group. Care coordination and medical home-community linkages are a big piece of P-TCPI and we are helping to link the many community and DOH grant activities like LAUNCH and the family WA Leadership Initiative back to the P-TCPI. Kate helped initiate a discussions in December with NE Tri LHJ and the P-TCPI regional practice facilitator about medical home collaboration opportunities. Each of the 9 TCPI regions has a practice facilitator who public health nurses and others can connect with to make sure participating clinics and behavioral health specialists know about your services for children with special needs.

- As part of the **Healthier Washington** initiative, DOH, University of WA and Qualis Health are developing a Practice Transformation Support Hub for primary care providers (but not specifically focused on children). Kate is meeting with Transformation Hub staff over the next few weeks to learn more about their activities and how the two efforts can support each other, especially around community resources. (FYI- excellent webinar 1/10 on behavioral and medical integration- the recording will be posted on new transformation hub website coming in late January) [http://www.hca.wa.gov/about-hca/healthier-washington/practice-transformation-support-hub](http://www.hca.wa.gov/about-hca/healthier-washington/practice-transformation-support-hub)

- **WA State of Reform Health Conference January 5**- Kate went hoping to learn what to expect with health transformation efforts. Not surprisingly, there is no certainty about what will happen in DC, but WA planning to move
ahead with Healthier WA. The 1.5 billion dollar Medicaid waiver for Washington State has just been signed by the Centers for Medicare and Medicaid Services and there are opportunities to propose innovative pilots through the 9 regional Accountable Communities of Health (ACHs). ACH organizations are now off the ground but vary widely. This is a good time for pediatric voices to get involved. Each ACH submitted a current Fact Sheet which give really helpful overviews (http://stateofreform.com/featured/2016/12/a-survey-of-achs-in-washington-state/0) Kate attended an interesting Care Coordination workshop which was a helpful reminder that there are evolving care coordination resources for children and adults with disabilities through Medicaid Health Homes and for youth over 18 through the Area Agencies on Aging (many of which contract with Health Homes). http://www.agingwashington.org/

Child Health Note

- Most recent CHN: Speech Disfluency and Stuttering in Early Childhood
- First quarter 2017 upcoming CHN – Lead Screening- a topic nominated by several Communication Network members at a fall meeting. Elizabeth Long, DOH Lead Screening expert, has drafted a CHN that we are now having reviewed by clinicians.
- All CHN topics: http://medicalhome.org/stateinitiatives/child-health-notes/child-health-notes-topics/

HEALWA: Health Evidence Resource Website for Washington State

Did you know that if you are a licensed health care practitioner in Washington State you can access online medical and nursing journals for free? You’ve already paid for this resource with a small portion of your state licensing fees. HEALWA assures affordable, anytime, online access to current, authoritative clinical information and educational resources to eligible health care practitioners in Washington State. The website is maintained by the UW Health Sciences Library in partnership with the Washington State Department of Health. https://heal-wa.org/

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
dep.ts.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. Nutrition Network Training – This fall 11 Registered Dietitian Nutritionists (RDNs) joined the Nutrition Network for Children with Special Health Care Needs. RDNs working in Okanagan, Yakima, Kennewick, Wenatchee, Friday Harbor, Renton, Spokane, Centralia and Seattle participated. These RDNs work in a variety of settings including WIC, public health, local/regional hospitals, community health clinics, and home health.

2. NN members and CSHCN Coordinators were invited to a webinar of the CHDD Fall Nutrition Journal Club on December 5, 2016. The article presented discussed the new 2015 released Down Syndrome growth charts and the best BMI data set to use with the DS charts (Note – Recommend for over 2 years of age use CDC growth chart BMI data).

3. Nutrition Network Webinar – This annual event is scheduled Friday, February 10, 2017 from 11:00 to 1:30 p.m. The webinar is open to Nutrition Network members and CSHCN Coordinators to join; however, they can invite others to listen/watch with them.
   The agenda:
   - Heather Twible, RDN, CD – Carbohydrate Malabsorption
   - Elizabeth Kirk, Ph.D., RDN – Vitamin D Update

4. A topic survey for the spring Nutrition Network meeting on Monday, May 22, 2017, in Renton, is being completed by NN members at this time.

WA Community Feeding Teams

1. Transition from Hospital to Home for Infants at Risk for Feeding & Nutrition Concerns – At the second meeting on October 21, 2016 small groups identified priority actions and future needs from four broad areas; Discharge and Transition Planning, Family Support, Professional Knowledge and Skills, and Continuity of Care. Future actions TBD.

2. A topic survey for the spring WA Community Feeding Team gathering on Tuesday, May 23, 2017 in Renton, is being completed by team members at this time.

3. Sharon Feucht and Mari Mazon, along with Joan Zerzan, attended the WA Smooth Way Home (SWH) retreat on December 1, 2016. We attended since members of transition group noted above also participate in SWH and
suggested some common goals between the two groups. Links between the transition work and SWH are still being explored.

Other Activities
Mari Mazon, Joan Zerzan, Jamie Piatt, and Sharon Feucht met October 21, 2016 to formulate topics, groups to be surveyed, and questions to conduct a needs assessment for nutrition services for CSHCN across WA State. The survey has been formatted and is under review. It will be sent to Nutrition Network members, WIC RDNs, and others identified as participating in pediatric nutrition activities at the state and national levels through the Academy of Nutrition and Dietetics. Goal is to send survey out by end of January 2017.

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

Washington State Fathers Network (WSFN)
Louis Mendoza
www.fathersnetwork.org

- Annual conference held on October 8th. 45 people registered, 41 attended, for most this was their first Fathers Network Conference. The Network steering committee debriefed the conference on November 1 and will meet to plan next year’s conference on March 7th. A debrief was held with the Bellevue School District (office of Special Ed, office of Diversity) who had provided space. Also in attendance were representatives from the district’s special needs PTA. The district has again agreed to provide the space and work with the Network more closely to increase attendance. 10 dads filled out the Leadership Initiative consent form.

- A former Yakima Network member is starting a chapter in Ellensburg.

- The Partnership for Fathers and Families held its first network event on October 18. Over 60 people attend from over 40 agencies. The next event will take place on January 17 at Edmonds Community College.

- Work continues with the Girl Scouts and Boy Scouts to have them be more inclusive of children and youth who have special health care needs. The Girl Scouts have developed a training manual and videos for staff and troop leaders. The Boy Scouts are arranging for community conversations to learn how their organization can best serve individuals with special health care needs and their families. The first of these conversations will be in Bellevue on Jan. 24.

- Met with staff from Arts Fund, City of Seattle Office of Arts and Culture and 4 Culture (the King County office of Arts and Culture) to discuss greater access to the cultural community for individuals with special health care needs and their families. All were in agreement that there is a gap in service. How to fill that gap is the focus of future conversations. Two ideas are to have focus groups to learn what the real and perceived barriers to access are and to have informational/training sessions for cultural organizations on what they can do to provide greater access.

- The respite program at the Bellevue YMCA concluded its 3 month pilot program. There were 14, 14 and 10 youth and families served respectively in October, November and December. Feedback from the families was very positive. The task force will next compile information and a recommendation to pass on to the Bellevue Y board and then to the King County Y management team. The hope is to have the program expand, not only in Bellevue but to other Y facilities in King County.

- Took part in a teleconference regarding the planning of a Fatherhood Summit being considered for late in 2017. This effort is being led by Frontiers for Innovation.

- Attended a Welcome Inclusion Initiative forum to learn more about the effort to create a welcoming community in Seattle for the athletes, families and coaches coming to Seattle in 2018 for the National Special Olympics.

Additional Update: Prompted by the fact that the Special Olympic USA Games will be held in Seattle in 2018 the Welcome Inclusion Initiative (WIN) was created. This is a two year campaign to create a welcoming environment in the Seattle/King County area for the thousands of athletes, families and coaches who will visit the area as part of this Special Olympics event. Primary elements of the campaign are to provide individuals and families with tools to identify and connect to local businesses who provide an inclusive environment and to educate and support local businesses to provide that welcoming environment. (See Attachment #9 for additional information.)

DISCUSSION FOLLOW-UP: The Special Olympics Washington contact is Chara McElfresh. She is on the Steering and Program Evaluation Committee’s for Washington Statewide Leadership Initiative (WSLI) and there are a number of items on the WSLI SharePoint site related to the care coordination type activities that she is involved in—for example, she actively promotes tabling at special Olympics events and promotes opportunities for organizations in the local community to share the resources of their organization in the local community at Special Olympics events. Chara also is a member of the Developmental Disabilities Council (DDC) Informing Families workgroup and a number of her events and her work are promoted through their site, under recreation. The calendar for Special Olympics WA is also linked to the WSLI SharePoint site so that folks can see where and when the Special Olympics events are in case they would like to have a table. Special Olympics WA also maintains a speaker’s bureau which Chara coordinates, if anyone would like to have a self-advocate speaker at their event.
Washington State Parent-to-Parent (P2P)
Susan Atkins
www.arcwa.org

Check out our website: www.arcwa.org click on the
Orange heart and you will find a listing of all Programs and Contacts

Parent to Parent Programs are working on the following with DOH:
1. WSLI – Washington State Leadership Initiative and SharePoint site
   - Encouraging family leaders in our state to be involved in activities so that they might influence policy and practices in state and federal government systems
   - Work on training these leaders and how to notify them of opportunities
   - We have an internet site with 575 of our trained Helping Parents listed by child’s disability that we can contact for matching but also to let know about opportunities; have started a e-group for Helping Parents
   - Learning lots about family leadership and sharing info on the SharePoint site
2. Project LAUNCH in 3 county Programs- all working with childcare centers and Head start too share resources for families, encourage developmental screenings of children; 2 counties have added Hispanic Outreach and one county is working with military medical personnel and resources
3. Autism AS3D grant- brand new; have 3 Coordinators interested in being Involved with this effort; King, Clallam, Yakima
4. Working with Seattle Children’s Hospital on sharing their training called- “Telling Your Story with a Purpose”. So far King, Kitsap/Jefferson, Spokane and Pierce counties are signed up to host this training.
5. Hosted a webinar for Programs to share their evaluation tools. Will be developing an Evaluation Tool that can be used by Programs. Discussing possibility of “following a family for one year” See if we learn more about how our Programs increase their emotional well-being, their resiliency, feeling of belonging, help parenting their child etc. Michelle Hoffman has shared a lot of good articles on this topic for me to look at.
6. Met with Father’s Network and Special Olympics Washington, to hear about their 2017 plans and how we can partner together better.
7. Talking with DDA about the new waiver service called Peer Mentoring. And how Sponsoring Agencies could bill Medicaid for this new service. It is different than a one to one Helping Parent match, it is where a Parent Coordinator would develop a plan for the child, to increase their knowledge of community resources and get them more involved in their community. The parent then would use this Plan for their child. We are also talking with DDA and DOH about how we can let parents and case managers know that this is a new service available in the IFS Waiver.
8. Requesting a budget increase for our Parent to Parent Programs with the legislature this new session. Senator Walsh and Representative Senn will be helping us work on this. Started 2 new Programs last year and have possible 3 new Programs for this coming year and need more funding to “enhance our current Programs”.
9. Working with Michelle Hoffman at DOH on the parent leadership project.
10. Working with DSHS-DDA on evaluation and may consider asking to evaluate services over time.
11. Susan will provide additional information around how to bill for peer mentoring and care planning through DDA.

Family to Family Health Information Center (F2FHIC)
Jill McCormick
www.familyvoicesofwashington.com

Funded through Health, Resources, and Services Administration (HRSA) for the support and training around Children and Youth with Special Healthcare Needs.
Grant Cycle: June 1, 2015 – May 30, 2018

This quarter F2F has done:
- Additional outreach into tribal communities in Clallam County, Kitsap, Jefferson, and King Counties.
- Outreach towards Diabetes Family Wisdom sites for Native American families in Pierce through SPIPA and Cowlitz centers. (Patient Centered Outcome Research) PCORI grant in tier II waiting on tier III award.
- Is partnering with Parent to Parent Centers in Pierce, Whatcom, and Chelan/Douglas for family information programing and outreach.
- Had conversations with Healthcare Exchange Tribal Liaison Program Director around how to locate and outreach to Urban Indian population around enrollment and accessing care.
- Participated in Western States Regional Genetics Collaborative
- State wide family leadership groups participation in Mental Health and Children with Special Healthcare Needs
Communication Network Meeting Minutes  
January 12, 2017

- Did trainings for state wide Parent to Parent Coordinators and Washington Dads group
- Resource Fair outreach in Pierce, Douglas, King, Clallam, Okanogan, and Jefferson Counties
- Participation with Open Doors, the ARC, OSPI, and HCA in a Language Access for IEP’s and 504 meetings bill workgroup with Representative Orwall
- Collaborating with the Northwest Downs Syndrome Association on their All Born In conference and some additional outreach in the state in the coming year

F2F also supervises a contract for Salish Behavioral Health Organization around the Family, Youth, System Partner, Round Table project for Mental Health services (FYSPRT). During this quarter the activities have been:
- Pulling together an area assessment of mental health services through support with Washington State Community Connectors
- Participating in trainings with Department of Behavioral Health and Washington State Community Connectors
- Working to build a Regional Tri-Lead team
- Setting website and dissemination materials
- Outreach in Kitsap, Jefferson, and Clallam Counties
- Starting of local and regional meetings

PAVE changing how they provide support to families; developing an intake system for call-ins and e-mails to filter those families initially to determine who they should get referred to.
- Working on enhancing connections;
- Making website fully ADA compliant.

Open Doors for Multicultural Families
Ginger Kwan
www.multiculturalfamilies.org

Ginger Kwan was unable to attend.

Office of Superintendent of Public Instruction (OSPI)
Robin Fleming
Program Supervisor for Coordinated School Health
healthyschools.ospi.k12.wa.us/waschool/

See Attachment #10 for PowerPoint slides.
Shared information on OSPI Nurse Corps. For details see: http://www.k12.wa.us/HealthServices/SchoolNurse.aspx

Neurodevelopmental Centers (NDCs) Update
Marianne Bastin, Good Samaritan Hospital, Children’s Therapy Unit

The NDC directors are most immediately concerned with the elimination of DOH funding to the NDCs as noted in Governor Inslee’s proposed 2017-19 budget. Total funding is $1.3million that supports 18 centers. NDC directors will be developing a plan to encourage the reversal of this proposal including speaking with our legislative representatives. We would appreciate any support from our CSHCN partners who can speak to the benefits of the NDC programs.

Birth to Three Developmental Center
On November 21st Birth to Three Developmental Center opened a high quality, inclusive child care center that will serve all children birth through age five. The child care program is designed to support physical, cognitive, communication and social/emotional development for all children ages 4 weeks though age five. Birth to Five Early Learning Center is located in NE Tacoma and we are licensed for 79 children. Our address is 4616 45th Avenue NW, Tacoma, WA 98422. Our Hours are 6:00 am-6:30 pm. Families can call the daycare at (253) 927-2026. We accept DSHS.
Children’s Therapy Unit- Good Samaritan
- We have hired an additional speech therapist, physical therapist and have an open position for a PT assistant. We continue to have long waitlists despite having more staff and seeing more patients per therapist.
- As of November 73% of children received their first appointment within 30 days of referral. Patient volume has grown 13% compared to last year and 8% of that growth is related to the implementation of Treatment Pathways.
- In December we had our first 5 children assessed in the movement lab. Muscle activity (EMG) and movement patterns (kinematic) during walking were assessed with the help of a contacted biomechanist and Dr. Robert Cooper who was trained at Gillette Children’s. We hope to have the movement lab fully open by mid-2017.
- Our pilot transitional clinics, to create a transition plan for children moving into adult medical services, was highly successful and is now being developed into an ongoing program which we hope to have running by early 2017.
- The pilot to use the WeeFIM as an outcome tool and as a means to design quality improvement plan continues and will be fully utilized by all therapists by mid 2017.
- We continue to rely on fundraisers and great relationships with our community to support our program needs.

Holly Ridge Center
The Infant Toddler Program will be starting out the new year with a new part-time ARNP, Frances Malone. After having Patti Schroeder as an ARNP on-site for 30 years, staff truly valued this position and support and we are excited to have found Frances! We will go through the process of individually credentialing her through each insurance and hope that we will be able to bill for many of her services. Holly Ridge has been asked to participate as a mentor for the Center of Excellence for Autism process through the newly obtained AS3D grant at the DOH of health and are eager to get to work on this. We are very proud of our Autism Program, but truly understand the challenges of getting such programs up and running and know that the reimbursement rates through insurances do not cover the cost of running effective programs. Holly Ridge has been sponsored recently by two different entities, The Habit Burger and Kitsap Kid’s Dentistry, to acknowledge our work in the community. Without the support of the community and fundraising, we could not continue to provide the extensive, outstanding services we provide.

Innovative Services NW
Innovative Services NW continues to serve Clark County in Early Intervention as well as outpatient pediatric therapy. We are excited to announce the November 2016 relaunch of Intensive Physical Therapy with Jessica DeLong, long term pediatric PT who recently completed her formal Intensive training. She had trained with our former Intensive Therapist, but is now fully certified and serving children who benefit from the intensive PT.

Challenges… Innovative Services has openings for a PTA and Special Education teacher – Early Intervention Specialist, both of which have been long term openings. There has not been one qualified applicant for the teacher position since posting the position in September. Pediatric Physical Therapy Assistants are also difficult to come by, even by staffing agencies.

Questions… the forthcoming changes in Early Intervention and NDC carve out has us posing many questions and concerns for the coming years.

Kindering Center
Kindering provides many services for children and families in need.
- Provides Vision Screening
- Provides Dental Screening
- Mental health counseling
- Support groups for mothers, fathers, grandparents, siblings
- Developmental Pediatrics Evaluations
- Center of Excellence for Autism
- Nutrition
- OT/PT/SLP
- Parenting classes
- Special Instruction
- Applied Behavioral Analysis
- Equipment Loans
- Orthotics Clinic
- CHERISH Foster Care Support
- SPEAKER Series 2017

Help for families that want to learn in 2017 –Kindering’s Speaker Series in cooperation with Allegro Pediatrics
- January 25th Bothell - Toddler 101
- February 15th Bellevue - Planning for the Future – wills, guardianships and special needs trusts
• April 26th Bellevue - Preservando la Cultura Latina: Criando a Nuestros Hijos en Los Estados Unidos - Spanish presentation
• May 31st Bellevue - Feeding a Toddler
• September 27th Bothell - Moms helping Moms
• October TBD

Handouts are available at the reception desk of both locations and from colleen.willis@kindering.org
For a full description check out our website link- https://kindering.org/portfolio-items/speaker-series/

Mary Bridge
MB has hired a COTA, per diem OT, and PTA.
OT has started three groups:
• Feeding Group: 18-24 month old
• Social Skills: 7-9 year old
• Movement: 3-4 year old

Speech is conducting a telemedicine pilot. Speech has had an over 30% increase in inpatient volume while maintaining outpatient volumes.
PT/OT/ Speech all continue to struggle with cancelations and NS. All groups continue to have waitlists.

Peace Health Children’s Therapy Bellingham
New staff: We hired a new Occupational therapist.
Providing new services: Working on ADOS testing.
Challenges we are having: Difficulty hiring therapists…very few applicants
What is going well: Great collaboration with our Pediatricians since they are located in the same building and have the same management.

Spokane Guilds’ School
Cover page of Visions newsletter is attached with recent news and stories. You can find the entire newsletter at http://www.guildschool.org/2016-vision-newsletters. (See Attachment #11)

Valley Medical Center
What’s new: Agreement with Renton Area Youth Services (RAYS) – now providing social work and family therapy 3 days per week in our center.
New Staff: hired new SLP and New PT – have positions open for 2 more SLPs and 1 OT
New services: Integration Listening (iLS) and toy adaptation
Challenges we are having: hiring staff, reimbursement concerns– Evicore is quite difficult. Nutrition payment continues to be difficult. Reimbursement for ADOS low (no more than regular evaluations despite increased time needed). Slowness getting staff licensed.
What is going well: Great staff and new hires; great community support and families.
Where we need help: NDC funding is slated to be cut in Governor’s budget.

Children’s Village – Yakima
• Jackie McPhee is retiring on March 1, 2016. We wish her well in her retirement and will miss her.
• Children’s Village is working on the new ICD-10 evaluation codes for Physical Therapy starting January 1st.
• Memorial Hospital has officially merged with Virginia Mason. Our new name is Virginia Mason Memorial or VMM
• The Early Intervention program is the largest home health service at Virginia Mason Memorial and is receiving 50-80 referrals a month.
• Staffing:
  o New hires
    • Occupational Therapist –We are fully staffed in this area for the first time in 3 years.
    • PT-A –for EI and Pediatric Therapy Services
    • Deaf Educator for Early Intervention
    • EI Support Staff – Newly crafted position to provide support
    • SLP-A for Early Intervention- newly developed role to increase frequency of speech services
• EI and VMM has recently been audited by Joint Commission. We are now taking the opportunity to improve the health of the community by:
  o Health Surveillance
  o New admission packets: cover your cough, RSV, Hand washing, bag techniques, onboarding requirements
• Interdisciplinary and group services include:
  o Munchkin Music group @ YMCA (Ed)
  o Music Talk and Play x2 @ YMCA (SLP, OT, Ed)
ESIT Staff Updates: We are pleased to announce that Sue Rose has accepted the position of Family Engagement Coordinator and started work on January 3. Sue has worked on behalf of children and families for over fifteen years through maternity case management, community mental health, and home visiting. She joins us from DEL’s Early Childhood Education and Assistance Program (ECEAP) where she worked as a Pre-K Specialist supporting contractors around the state in providing quality comprehensive services to children and families. She has her Bachelor’s Degree from Pacific Lutheran University and she earned her Master’s Degree in Counseling Psychology from St. Martin’s University.

Sue enjoys: Thinking of creative ways to bring people together in collaborative ways.

Sue prioritizes: People, relationships, and the present moment while keeping the end-goal in mind.

Sue reads: Mostly non-fiction books on how to be a better version of herself – but would love to hear some great fiction recommendations! 😊

Please send her an email to welcome her to her new position and give her one piece of advice that will help her be the most successful in her role! Her email address is Suzanne.rose@del.wa.gov

A special thank you goes out to the parents from the Family Leadership and Involvement Committee (FLIC) who participated on the interview team and helped us select the best candidate for this very important position.

Annual Performance Report: ESIT is finalizing the Annual Performance Report (APR), due to the Office of Special Education Programs (OSEP) on February 3, 2017. A special APR review meeting will occur on January 18, 2017 to obtain State Interagency Coordinating Council feedback.

Annual Application for Federal Funding: ESIT will apply for FFY 2017 funding in April, 2017. As part of the application process, ESIT is required to hold a public comment period prior to each year’s application submission. The 30 day public comment period, prior to submitting the application, will be held in February or March, 2017.

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 March 21, 2017 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 January 18 from 9:00-3:00 at navos, 1210 SW 136th St, Burien, WA 98166. There is a webinar option for those who can’t join in person. This is a special meeting to review the federal Annual Performance Report (APR). Contact Jahla Brown at (360) 725-4413 or email Jahla.Brown@del.wa.gov for more information or to R.S.V.P.

Nicole Fergason was unable to attend.
DSHS, Fostering Well-Being Care Coordination Unit (FWB CCU)
Michelle Milholland-Fears

FWB is business as usual with the announcement that we will be looking for another RN in the near future (unsure of exactly when, but we have someone leaving this month and will need to fill their spot).

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

Grandparents and Relatives Do you know about the services and supports for you and the children in your care? (DSHS 22-1120x) This six page pamphlet provides a comprehensive list of various resources, benefits, and support services available to relatives raising children. English, Cambodian, Chinese, Korean, Laotian, Russian, Somali, Spanish, and Vietnamese (PDF) (English and Spanish copies can be ordered)

On our kinship website we have all 8 languages posted. Folks can order the pamphlets, instructions on back side – in English and Spanish. https://www.dshs.wa.gov/altsa/kinship-care/dshs-kinship-publications

Any feedback or recommendations for a next version can be sent to Hilarie at hilarie.hauptman@dshs.wa.gov.


See Attachment #12 for 14th Annual Voices of Children Contest. Voices of Children Raised by Grandparents and Other Relatives is a contest for children with Washington State who are being raised, now or in the past, by a relative other than their parents. The contest honors both the children, and the more than 45,000 grandparents and other relatives in Washington State who are raising them.

Lifespan Respite Washington
Linda Porter
www.lifespanrespitewa.org

Linda Porter was unable to attend.

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)
Allison Templeton, Grant Coordinator, and Jen St. Cyr, Family Support Coordinator at WithinReach will be facilitating a workgroup throughout this grant year to explore outreach, collaboration, and engagement for partners and families. This is in lieu of the Great LINCS steering committee formerly held immediately following the communication network. Our next meeting is on Wednesday, January 25th. Let us know if you are interested in attending or learning more!

At WithinReach we recognize that special needs are basic needs, and that accessing resources to support those needs is often challenging. We want more people to hear about the experiences of families navigating the many systems involved in the lives of kids with special health and developmental needs – and how great those kids are! We are looking for families to participate in a podcast (short recorded audio sessions) series. What's your story? We want to hear from you, to help your voice be heard. Please contact our Family Support Coordinator, Jen St. Cyr, for more information and to learn more about our Family Stories project: 206-830-5173 or jennifers@withinreachwa.org.

ParentHelp123.org now features a dedicated Special Needs tab in our top navigation bar. This update to our website is in response to user testing and feedback from clients and providers. Families and providers will now more easily be able to access information about special health and development needs and resources in Washington State. If you have content...
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that we can help showcase on our new tab, please contact Jen St. Cyr. We are in the process of creating a direct referral portal on the Special Needs landing page that will allow individuals to submit a request for a direct call back or email from our Family Support Coordinator.

Child Development
WithinReach's Child Development Coordinator, Stephanie Orrico, and Family Support Coordinator, Jen St. Cyr, worked with the University of Washington Bothell's Data Visualization course through December. We explored how and when families are engaging in resource search/access so that we can better support them and improve outreach and communications strategies. The resulting data snapshots, using the national Survey of Pathways to Diagnosis and Services, provided compelling talking points. For example: "Parents had the first concern that something was not right with the child's development by about five times more than the other categories [teacher, counselor, health care provider, other]". We look forward to collaborating more with the students as the year continues.

We now have the Ages and Stages Questionnaire: Social Emotional available via direct link on ParentHelp123.org: http://www.parenthelp123.org/child-development/child-development-screening-public. In addition to the general ASQ, WithinReach offers the ASQ:SE to look specifically at how kids manage their emotions, communicate their needs, interact with others, and behave in safe and appropriate ways. If you have questions or concerns about a child's social or emotional development, this tool is a great next step. When you submit a questionnaire, a child development specialist from WithinReach will call you to discuss the results, recommend activities and explore other resources.

Maggie Kizer, Bilingual Child Development Specialist, is on maternity leave until March (welcome, baby Eli!). Maritza Cazares, Bilingual Outreach and Enrollment Specialist, has been trained on the Ages and Stages Questionnaire and is looking forward to the opportunity to support Maggie’s clients while she is on leave.

THrive Washington
Liv Woodstrom
thrivewa.org

Liv Woodstrom was unable to attend. She does plan to attend future meetings.

DOH Screening and Genetics Unit
Deb Lochner Doyle
www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/GeneticServices.aspx

Introduced new staff member Nirupama Shridhar (Nini).

UW Exploratory Funding and The Human Library Update
UW School of Public Health allocated $25,000 to explore the possibility of setting up a Genetic Counseling Training Program. It would be the first such program in the Pacific Northwest. The Screening and Genetics Unit, is hosting a meeting in partnership with UW to begin planning for the Genetic Counseling Training Program on February 3rd. One concept we will discuss is known as The Human Library. It involves partnering students with individuals with a genetic condition or parents of child with a genetic conditions to learn more about lived experience. The genetic counselor-in-training will then be asked to write-up how they might present information about the condition to a prenatal patient using non-directive language. This script would be critiqued by faculty as well as the “human book.” The goal being to have students truly appreciate the heartache as well as the joys of all lives and be able to communicate factual unbiased information effectively. We are still finalizing the agenda for the meeting, but from a broad overview, we will be working on innovative methods of curriculum delivery, supervisory training methods, and getting a better understanding of the resources required to set all of this up.

Pilot Project with MultiCare
The Screening and Genetics Unit is working with MultiCare Health Systems for a Quality Improvement project around cholesterol screening for 9-11 year olds. The project aims to identify barriers in pediatric lipid screening, and to compare the strategic value of two different interventions aimed at increasing the proportion of children screened per current American Academy of Pediatrics (AAP) Guidelines. Lipid screening in this age group is important to identify children and their parents affected with Familial Hypercholesterolemia – one of the most common genetic disorders in humans that is a leading cause for early cardiovascular disease. We are in the process of finalizing the contract.
Dissemination of Down Syndrome Materials
We have had three requests to date for the Down syndrome book: 1 midwife and 2 doctors. The Down Syndrome local resources list on our webpage was accessed 70 times in 2016. (Law went into effect late June 2016).

EHDDI Unit Updates
The CDC will be using Vital Signs to increase awareness about non-occupational noise induced hearing loss. In February they will have a town hall teleconference that will feature this topic and the CDC is looking for lessons learned and success stories from states on how they have tackled prevention of noise-induced hearing loss. On June 20 there will also be a CDC Grand Rounds on “Promoting Hearing Health Across the Lifespan.” If you are aware of any projects in Washington that address non-occupational noise induced hearing loss, please contact Karin Neidt at the EHDDI program (Karin.Neidt@doh.wa.gov or 206-418-5609).

Announcements

1. The Washington State Apple Health Managed Care Organizations compiled a flyer to share information about the benefits of an Early Periodic Screening Diagnostic and Treatment (EPSDT) or well-child visit. See Attachment #13. For further information contact Kate Cross at kate.cross@doh.wa.gov.

2. The Washington State Independent Living Council (WA SILC) Regional Alliance for Resilient and Equitable Transportation (RARET) Workgroup is conducting 3 upcoming training opportunity for Transportation Providers, Emergency Managers, Human Service Providers, and others interested in accessible disaster transportation in Snohomish (1/27/2017), King (2/3/2017), and Pierce (2/10/2017) Counties. This tabletop is targeted towards Transportation Providers, Human Service Agencies, Emergency Managers, and Healthcare Facilities. The RARENT Workgroup encourages everyone to participate, regardless of ability. For accommodations or accessibility information, contact Zoë Jorna at 425.943.6730 or zjorna@hopelink.org. Please see the attached 2017-TransportationWorkshopFlyer for additional information. See Attachment #14.

3. The following is an article that was printed in a Clark County Newsletter. Kuddos to Connie Callahan, CSHCN Coordinator in Clark.

Helping kids with special healthcare needs thrive
Last summer, Public Health nurse Connie Callahan arranged camp experiences for nine children with special healthcare needs. Using federal Maternal and Child Health block grant dollars, she was able to provide education and recreation opportunities for kids whose families would not have had the resources to send their child to such a camp.

The children attended different summer camps for a total of 26 weeks. Several attended Vancouver Parks and Recreation’s summer sensory day camp for children ages 5-12. Activities included field trips to the Oregon Zoo and Oregon Museum of Science and Industry, swimming excursions and other outings. Each child was assigned a staff member and registered nurses were available, if needed.

A child newly diagnosed with diabetes attended a one-week camp for children with diabetes. In addition to learning about diabetes care, he enjoyed making friends with other children like him. Another child attended PKU camp, where he learned about his blood disorder, Phenylketonuria, his special diet and how to live as a teen with this diagnosis.

Connie hopes to send more kids to camp next summer.

“The joy and excitement of these kids was beyond words,” said Connie. “One mother said her son now was smiling on his way to camp and when she picked him up from camp. Each one of these kids wants to attend summer camp next year.” Don Strick, Public Health

4. From Amy Carlsen, RN; Parent Professional Partnership

As the Family Faculty for the University of WA LEND, I have been sharing my story of raising a son with autism for many years. A few years ago, Josh asked that I don’t talk about him anymore. Over these past years he has really struggled with not wanting people to know that he has autism yet not really fitting in anywhere. This past month he finally decided to talk his disability. He created this 2 minute video sharing his struggles with autism. It was presented at the Martin Luther King assembly at his high school, Nathan Hale. His words are raw, honest, and powerful. I’m very proud of him! Enjoy! https://www.youtube.com/watch?v=gJMHKLZ4HKQ
Attachments

1. Healthy Starts and Transitions PowerPoint Slides
4. Northwest CSHCN Region Minutes
5. Southwest CSHCN Region Minutes
6. Central CSHCN Region Minutes
7. East CSHCN Region Minutes
8. P-TCPI PowerPoint Slides
9. The Welcome Inclusion Initiative (WiN) Flyer
10. OSPI PowerPoint Presentation
11. November 2016 Vision Newsletter, Spokane Guilds’ School and Neuromuscular Center
12. 14\textsuperscript{th} Annual Voices of Children Contest
13. EPSDT instead of Sports Physical Flyer
14. Adverse Weather Tabletop Exercise Flyer

Next CSHCN Communication Network Meeting
Thursday, April 13, 2017
Creekside Two at Centerpoint
20425 72\textsuperscript{nd} Avenue South
Kent, Washington
Conference Room 309