CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROGRAM
COMMUNICATION NETWORK MEETING
October 13, 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.

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Communication Network Meeting Minutes  
October 13, 2016

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Children with Special Health Care Needs (CSHCN) Program Update  
Maria Nardella  

CSHCN Program Updates

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

MCHBG Consumer Input Survey
Thanks to those of you who promoted this survey after our July CommNet meeting! A public input survey was developed by the MCH team in collaboration with communications staff in order to make it as accessible as possible. This survey was posted on the DOH website from May through August 2016 on popular pages for the MCH population, and was also disseminated via Twitter and Facebook. Partners were asked to send the survey to their clients to increase our reach.

Overall, we received 175 responses and 104 completed surveys from consumers on topics including reasons for not getting an annual well-women visit; breastfeeding challenges and barriers; knowledge of safe sleep practices; coordination of care for children and youth with special health care needs; and adequacy of health insurance. The input has given us a sense of consumers’ priorities around our chosen national performance measures and state performance measures, and will help us shape our activities as we move forward. Feedback from consumers also indicated a need to improve communication about our work to our consumers. The MCH team has had two initial meetings in July and August 2016 to discuss how best to convey information about our work to MCH consumers in our state, and we will continue these discussions throughout the year.

Survey results can be accessed here: [http://www.doh.wa.gov/Portals/1/Documents/8330/140-138-PublicInputSurveyResultsWebsite.pdf](http://www.doh.wa.gov/Portals/1/Documents/8330/140-138-PublicInputSurveyResultsWebsite.pdf)

State DOH Budget Update
DOH's number one priority is an immediate investment in the public health system (Foundational Public Health). This investment will fill critical gaps in essential public health services and is the first step to stabilize and modernize the public health system. The funding request will restore key functions that have been lost, and improve public health’s ability to respond to the threat of communicable and chronic diseases. Some of the remaining DOH budget requests funding for:

- Continuing the Healthiest Next Generation initiative.
- Responding to the Hepatitis C Epidemic.
- Addressing lead concerns outlined in Governor Inslee’s Directive

Transforming Clinical Practice Initiative (TCPI)
Maria Nardella has been actively involved with TCPI working to bridge practice transformation activities with the CSHCN Program. The Medical Home Neighborhood Team is still being formed through a contract with Children’s Village, with two initial "Go To Meetings" held with interested team members in September. Proposals are being considered to address collaborations through the grant to improve care coordination issues on practice, regional, and statewide levels. Four-year grant.

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

Autism and other Developmental Disabilities (AS3D) Grant
Great news: DOH's Healthy Starts and Transitions Unit, CSHCN Program was recently awarded a federal grant from the Health Resources and Services Administration, Maternal and Child Health Bureau to improve access to coordinated, comprehensive systems of services that leads to early diagnosis and entry into services for children with autism spectrum

Back to top
disorders and other developmental disabilities within the state and their families, emphasizing medically underserved and rural populations. The grant is $420,000 per year for three years and will focus on systems integration, family navigation and leadership, and policy reform. Grant activities will support expansion of efforts to improve screening for autism and other developmental disabilities, including the CME-accredited Great MINDS (Medical Homes Include Developmental Screening) trainings for pediatric primary care providers on the use of validated tools for developmental screening and how and where to refer children and families to needed services. The grant will allow us to modify the curriculum with additional autism-specific components and to provide additional trainings. This grant will also support expansion of Community Asset Mapping (CAM) activities, which provides help for communities to strengthen local systems to screen, evaluate, diagnose and provide timely intervention services to children with autism and other developmental disabilities and help communities identify how to improve communication and referrals to state diagnostic centers for more complicated evaluations. We are in the process of hiring a project coordinator, planning for the first national grantee meeting in Washington D.C. later this month, and planning a partner orientation webinar for November. Stay tuned!

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

**Washington State Leadership Initiative (WSLI)**
DOH has been working with community partners to create a statewide family leadership network to support training for leadership development, and connect trained family leaders to advisory opportunities at local, regional, state and national levels. At this time we have 3 working groups: 1-Steering Committee—this group plans the direction for the project and prioritizes project goals. This group predominantly meets via webinar monthly, with occasional in person meetings. 2-Program Evaluation Workgroup—this group meets monthly via webinar and is comprised of family led organization reps who are interested in learning more about program evaluation and how to create shared measurement in order to show the impact of our work to support family support and leadership development across the state. 3-Agency Backbone meeting—this meeting is monthly and is made up of state agency reps who are interested in expanding the culture of family and consumer partnership across state systems, and identifying opportunities to invite family and consumer advisors to inform their work. A SharePoint site has been created to facilitate networking and collaboration of statewide family leaders with shared tools and resources. A statewide meeting of the WSLI will be held on November 9th in Kent and Spokane—teleconferenced together to allow family leaders from across the state to participate. If anyone is interested in any information on workgroups, SharePoint access, or the November 9th statewide meeting, contact Michelle Hoffman at michelle.hoffman@doh.wa.gov.

**Essentials for Childhood (EfC)**
**Leadership**
In order to bring more cross-sector leadership and voice to the Essentials for Childhood Steering Committee, we are transitioning to a three co-chair structure. Co-chairs will drawing from the three broad sectors that participate in Essentials: State Government, Statewide philanthropy/business/advocacy, and Community. Secretary of Health Wiesman is continuing as the state government co-chair. We are working to fill the other two positions.

**Executive Director Opportunity**
Department of Early Learning has a contracted bid opportunity for an Executive Director. We are looking for an innovative, inspirational and adaptive leader who is driven to improve health and education outcomes for children. Anyone interested in this opportunity to submit a quote and qualifications for RFQQ 16-113, contact the RFQQ Coordinator, Kristy Brodersen, at del.contracts@del.wa.gov. You will be added to a list to be notified if more information is released about this opportunity. This RFQQ can also be accessed by registered Vendors through [Washington’s Electronic Business Solution (WEBS) system](http://www.doh.wa.gov/EFaC/).

**Essentials Workgroups**
- **Community & Stakeholder Education & Action** is focused primarily on developing strategies to create and support a useful connective tissue and learning infrastructure between and among all the amazing work happening everywhere around WA, locally, regionally and state level. They also recently sponsored 2 successful community café conversations about toxic stress in the South King County Somali Community.
- **Systems, Services & Implementation** has identified goals and started a workplan to support and inform successful implementation of Help Me Grow in communities.
- **Innovative New Policy & Financing.** A subgroup focused on trauma-informed/social-emotional learning has is identified a few possible actions and is working on next steps. The group, is also exploring opportunities to change TANF and other policies to support high-risk families. They are also interested in opportunities in the health transformation, particularly in the support of prevention activities by Accountable Communities of Health using the proposed Medicaid section 1115 Waiver.

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](http://www.doh.wa.gov/efc).
Great LINCS (Links to Integrate and Coordinate Care) for CYSHCN Grant
Great LINCS began its third and final year September 1st. The focus of year three will be promoting the shared resource (WithinReach) across the state. To accomplish this, GL will begin a Shared Resource Community Outreach Workgroup to leverage partner ideas. Great LINCS will also continue to work with ESIT around the new Medical Home Guidance.

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

Great MINDS Grant Updates
Great MINDS is currently scheduling trainings for the 2016-17 contract year. The next Great MINDS training will be in San Juan October 13th, followed by Whitman on November 2nd.

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

Project LAUNCH Expansion
Project LAUNCH is in full implementation with Element 1 of the grant, UDS Screening and Assessment. The UDS Tool Kit has been issued along with the Manual/User Guide to the trainers in each community. Each community has begun to reach out to the providers who we would like to see participate in LAUNCH activities. These providers are licensed child care providers who in early achievers and at a level 3. There have been a couple of trainings in two communities with providers and the next step are the parent nights (parents are learning about child development and screenings using ASQ 3/ASQ-SE3) The state and local lead continue to meet with 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. At the state level we are refining the evaluation plan, which a draft is due at the end of October 2016. Project LAUNCH has been asked to collect a little more data around our second element, mental health consultation. Currently we are weaving those indicators into our current evaluation plan.

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

Universal Developmental Screening (UDS)
- Upcoming Conference: “Improving Access to Developmental and Behavioral Screening, Assessment, Referrals and Services - Multiple Models”. The Early Childhood Comprehensive Systems grant at the DOH is convening a conversation around improving access to developmental and behavioral screening, assessment, referrals and services for all children in our state. We will highlight multiple models being used successfully with a focus on sustainability. Families will share their experiences with systems of care to inform our discussion about how we can adapt models to be more culturally responsive and inclusive of underserved populations. To join the conversation on October 17th in Tukwila, you can register at https://washingtonstateeccs.eventbrite.com. For more information, contact Christine Stalie (christine.stalie@doh.wa.gov).

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

Healthy Communities Consolidated Contracts Updates
Local contractors are implementing new individual work plans. In an effort to tell the statewide Maternal and Child Health Block Grant (MCHBG) story and to demonstrate the role of local public health, certain types of work happening in local communities is being measured:
- For Children with Special health Care Needs efforts, contractors will track outreach, training and technical assistance, care coordination, and systems development
- Contractors will document the sectors involved and the level of involvement by the contractor in any community group, project, project or initiative addressing Adverse Childhood Experiences and/or Universal Developmental Screening.

The effort is considered a pilot and will be evaluated after 6 months.

The 2016 MCHBG Regional Meetings are happening later this month:
October 18 – Island County Health Department: Coupeville
October 20 – Clark County Health Department: Vancouver
October 25 – Spokane Regional Health District: Spokane
October 26 – Grant County Health District: Moses Lake

These meetings are for county MCHBG coordinators and are an opportunity for gathering input, sharing information and facilitating networking between coordinators.

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

Back to top
Other:
The 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

**Health Care Authority (the Medicaid agency)**

Colette Jones and Kevin Cornell

Other Health Insurance: HCA is enrolling Medicaid clients with other health insurance coverage into managed care starting January 1, 2017 – representing about 30,000 members; 19,000 families. A general notification will be sent out soon for clients with other health insurance letting them know to expect this change. A client-specific letter will be sent in mid to late November with the specific MCO information and the Apple Health welcome booklet will be included with instructions on how they can change the MCO plan.

**What is the communication plan for both families and care coordinators? What about WithinReach?**

Will be notifying providers; Colette will send out information through the Communication Network. The Medicaid MCOs already work with other managed care organizations.

New managed care programs monitoring activities: Two new programs started April 1, 2016 and HCA is actively partnering with the MCOs involved to provide technical assistance and monitoring.

- Apple Health Foster Care: Coordinated Care for state-wide managed care for foster care and adoption support children and youth and foster care alumni.
- Fully Integrated Managed Care: Molina and CHPW for Clark and Skamania counties

Health Homes: HCA and DSHS are working to expand the Health Home program to the entire state. This will require expansion into King and Snohomish counties, which is planned to start January 1, 2017.

Integration: HCA and DSHS continue to work to integrate physical health, mental health, and substance use services in the Medicaid (Apple Health) program. Southwest WA (Clark and Skamania counties) was the first region to implement Fully Integrated Managed Care, which began April 1, 2016. The state is working with other regions to determine the next area for implementation of integrated care purchasing. For more information and Fact Sheets, see the [HCA Integrated physical and behavioral health care web page](http://here.doh.wa.gov/materials/flu-influenza/13_FluSpecial_V16L.pdf).

**Enrollment figures:** See *Attachment # 2 for Apple Health Enrollment Preliminary Report, August 2016*

Medicaid Transformation Demonstration project: HCA is working with the federal government to reach an agreement for funding of a 5-year demonstration project. It would allow flexibility to provide supportive housing, supportive employment, and long term care service enhancements as well as deeper investments in high quality, accessible health care and community based services. The Medicaid transformation demonstration—one of only a handful granted to states by CMS—will help accelerate Healthier Washington’s goals of better health, better care, and lower costs. As soon as it is available, HCA will post a link to the Governor’s press release on the [Healthier Washington Medicaid transformation web page](http://here.doh.wa.gov/materials/flu-influenza/13_FluSpecial_V16L.pdf).

Value-Based Purchasing: The Health Care Authority is working on value-based purchasing. Paying for value is one of the main Healthier Washington strategies to achieve the triple aim of better health, better care, and lower costs. Meeting this goal will require shifting reimbursement strategies away from a system that pays for volume of service to one that rewards quality and outcomes. To that end, Washington will drive 80 percent of state-financed health care and 50 percent of the commercial market to value-based payment by 2019. More information is available on the [Healthier Washington Paying for Value web page](http://here.doh.wa.gov/materials/flu-influenza/13_FluSpecial_V16L.pdf).
Cary Robertson was unable to attend.

Director of community management is leaving; lots of changes; working with members.

Coordinated Care CSHCN Case Management (CM) Team is performing outreach following up “safety net checks” for any child with a positive lead level testing in 2016. CSHCN CM's are performing outcome checks to make sure members and families received all Lab value rechecks and Lead exposure education.

There is lots of activity happening in Foster Care section. There are 700 children in case management and an Emergency Department Diversion project which is a special outreach to children who are going to the Emergency Room. Christy Schneck, new Foster Care Coordinator, attended the Communication Network meeting and will continue attending as a network member.

Quality Improvement making great strides at Coordinated Care.

Nikki Nordstrom retired; ED follow-up calls; special project on Asthma care – medications; bringing on a new pediatric case management; families need to contact the plan if ABA is not accessed – getting in within 4 to 6 months; can get kiddos into center based; but home based waiting list is 3 years
The United Healthcare provides a grant to families to pay for items such as wheelchairs or other medical equipment. The family does not need to be a member of United Healthcare. They just need to complete the application.

See Attachment #3 for a copy of the brochure for this program. I hope that you will share this with the families that you work with.

The Center for Children with Special Needs (CCSN) at Seattle Children's
Jacquie Stock
www.cshcn.org

- Welcome Hanna Abrahamson, the Center’s new Project Coordinator. Contact Hanna for Care Organizers, Starting Point Guides, Guía para Padres, County Resource Lists and other informational or resource needs from the Center. (Hanna.Abrahamson@seattlechildrens.org)

- Paul Gilmore, the Center’s Web Coordinator, is in process of constantly improving our site and sharing news via social media. Check us out at www.CSHCN.org and follow us on Facebook and Twitter. Paul is happy to help promote your news and events as well via our social media accounts.

- After at least 15 years of WA DOH CSHCN program funding, Seattle Children’s Outreach Education has now assumed work of posting and promoting online educational videos related to pediatric special health care needs at http://www.seattlechildrens.org/healthcare-professionals/education/online-grand-rounds/.

- Center staff represent WA DOH CSHCN and children with special health care needs at hospital’s Adolescent Transition team—exploring among many improvements, how to include an alert in the electronic health record for providers to know a transition to adult care plan should be started.

- Nurse Consultant Lynn Chernick, RN, MSN and Hanna Abrahamson will initiate work with Managed Care Organization care coordinators or other MCO representatives to learn what their resource and educational needs are for themselves and for parents of children and youth with special health care needs. (MCO folks—come see usJ! Thanks.)

- Resource list evaluation from summer 2016 – spoke with coordinators, WithinReach; some state level resources removed and county-based resources retained.

Medical Home Partnerships for CYSHCN and Their Families
Kate Orville
www.medicalhome.org

Universal Developmental Screening
- We are facilitating a panel discussion with Spokane and Snohomish UDS Community Asset Mapping coalition leaders at the DOH UDS meeting October 17th. The communities will share what they have done to improve access to UDS locally, how they have known it has worked and what has surprised them. They will also address sustainability through funding and creative partnerships, how to keep the work relevant to the community, and recommendations for moving UDS work forward in Washington.

- 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 'home-ness,' initially focusing on developmental screening for a vulnerable pilot group of young Somali children using the Survey of Well-being of Young Children.
Communication Network Meeting Minutes
October 13, 2016

(SWYC) screening tool. 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.

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

- Twelve communities submitted a team report outlining their goals and activities for October 1, 2015-Sept. 30, 2016. These communities are Adams, Benton-Franklin, Clark, Island, Kitsap, Lewis, Skagit, Snohomish, Spokane and Whatcom Counties as well as two pediatric clinics in King County, Odessa Brown Children’s Clinic and Harborview Pediatrics. Communities were eligible for payments of $350 for their reports. An additional five communities continue to collaborate with the project but did not turn in reports: Cowlitz, Grant, King, Walla Walla, and Yakima Counties. A summary can be found in the appendixes. (See Attachment #4)

- Amy, Kate and Kathy supported Jackie McPhee in facilitating a community meeting around care coordination for children with special health care needs in Yakima. We are helping with the development of a survey of care coordinators to be followed by a meeting of management representatives to identify issues and strengths with care coordination in the county and strategies for improving care. The results will also be shared with other efforts in the state to facilitate a coordinated system of care for children.

- 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, Spanish, Arabic, Chinese, Khmer, Korean, Russian, and Vietnamese. The Early Learning Division, Snohomish County, paid for translations. They can be found on the medical home website at http://medicalhome.org/stateinitiatives/community-asset-mapping/#exampleslocal

Pediatric Transforming Clinical Practice Initiative (TCPI)

- Kathy and Kate are participating in the WCAAP Health Care Transformation subcommittee; Kate and Amy are participating on the Medical Home Neighborhood Committee led by Jackie McPhee, Yakima Village. Kathy continues to participate in the WCAAP Early Childhood Subcommittee as well.

Child Health Note:

- We finalized the Child Health Note on Red Flags in Speech and Language Development that was posted at http://medicalhome.org/stateinitiatives/child-health-notes/. (See Attachment #5)

Innovation and Care Integration for Children and Youth with Autism Spectrum Disorders (AS3D) Grant:

- We helped with the development of the Healthy Transition’s AS3D grant and look forward to the project activities beginning.

LEND:

- The 2016-2017 UW LEND Fellows started in September. This includes a new Self Advocate Discipline with the Advocate Faculty, Ivanova Smith, and an Advocate Fellow, Alex Motteler
- We are working on a pilot program at LEND that will provide an opportunity for two parents from underserved populations to become medium term LEND fellows. These parents will do an abbreviated LEND Fellowship and provide input to LEND faculty on cultural competency and cultural humility.
- LEND will be piloting the “Adopt a County” initiative this 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/

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
depths.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

Back to top
Feeding Teams, as well as projects related to improving nutrition through medical nutrition therapy and addressing issues related to cost of and reimbursement for nutrition and feeding team services.

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

1. Nutrition Network Training – This fall the 21st class of registered dietitian nutritionists (RDNs) will attend NN training on Thursday, November 3rd and Friday, November 4th in Seattle. The eleven trainees work throughout the State of WA in public health and community health care clinics, hospitals, WIC, and home health care. Six are from eastern WA; one trainee is also a LEND Fellow, (LEND-is Leadership Education in Neurodevelopmental and Related Disabilities), at CHDD at U of WA.

This program, begun in 1987, continues to provide training for RDNs in WA State to increase their knowledge and skills related to nutrition services for CSHCN, family centered care, medical home, and nutrition in early intervention and schools.

2. Nutrition Network Webinar – We are planning topics for a 2.5-hour webinar scheduled Friday, February 10, 2017 from 11 a.m to 1:30 p.m. We invite Nutrition Network members and CSCHN Coordinators. NN members are choosing 2 of these five topics: update on Vitamin D, update on lead and nutrition considerations, outcomes for premature babies, cystic fibrosis or fructose malabsorption. These topics are based on suggested topics from program evaluations completed by network members.

**NICU-to-Home Nutrition & Feeding Transition Group**

This summer contract staff met with parents who had participated in the first meeting of this group. This meeting was to insure that parent voices were part of the group and the intent of the project understood by all. The entire group was surveyed based on concerns expressed at the first meeting. Responses have been narrowed to four priority areas- family support, discharge and transition planning, professional knowledge and skills, and continuity of care. Work will continue on Friday, October 21, 2016 to identify potential actions and/or resources to support the priorities.

**WA Community Feeding Teams**

Ten WA Community Feeding Teams were represented at a weeklong conference, the Fragile Infant Feeding Institute (FIFI), held in Tacoma this year. Two years ago 2 teams from WA were selected and funded to attend FIFI. Based on those team’s experience and several FIFI speakers that have presented in WA State we encouraged teams to consider attendance when the event came to our state. Sharon Feucht also attended FIFI.

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

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**Washington State Fathers Network (WSFN)**

Louis Mendoza  
www.fathersnetwork.org

- A closed Facebook group has been launched as a joint effort of WSFN, Dads Move, WA Dads, D.A.D.S., The Arc of King County and Parent to Parent. The group is called P2P Dads of Special Kids.
- Attended one day of the Dads Move dad training weekend on Whidbey Island.
- Kickoff the new school year family Pancake breakfast was held at the Kindering Bellevue office on September 10th. 34 family members attended.
- Began work on updating the Fathers Network website. Expected completion date is during the first week of October 2016.
- Summer BBQ with Arc of King County.
  - Date was moved and I was no longer able to attend so WSFN presence at the event was not official. Communications went out on July 29th and August 1st informing people of the change but encouraging dads to bring their families to enjoy the fish fry, games and good company. About 80 people attended but fewer than 10 dads.
- To increase outreach to dads whose children are receiving services at Kindering a target email messages went out and follow up phone calls were made to answer questions and encourage membership.
- The Seattle Chapter at Boyer and the Bellevue chapter distributed tickets for 3 Seattle Mariner games. The tickets were obtained by the Boyer Chapter facilitator.
- Interviewed by Within Reach about the Fathers Network for their blog.
- Continued attending meetings at the Bellevue YMCA regarding developing a free respite program for parents of children with special needs; drop off model for several hours. Pilot program is scheduled to launch on October 29. Application and additional information will be shared through the Communication Network.
• Notified on August 18th that the Fathers Network has been featured in the Best Resources for Parents of Children with Special Needs.
• Facilitated a discussion with the Parent Child Home Program staff at Kindering about engagement of fathers
• Co-presented a class on Being the Parent of a Child with Special Needs.
• Attended meetings held by Shanee Montague, of the DOH, on children with special health care needs age 5-12. Focus is on organizing a conference for parents and professionals.
• Attended WSLI steering committee meeting at Arc of Kitsap/Jefferson County.
• WSFN conference will be held October 8, 2016.

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**Washington State Parent-to-Parent (P2P)**
Susan Atkins  
[www.arcwa.org](http://www.arcwa.org)

1. Three new P2P Programs- contracts and orientation finished.
   a. Clallam County- Mosaic organization is sponsoring agency and hired Shawnda Hicks as Coordinator.
   b. Okanogan County- Okanogan Behavioral Health is sponsoring agency. Have an Advisory Board and working on hiring.
   c. Klickitat County- PEACE organization is sponsoring agency. Have an Advisory Board and are hiring this week.

2. Tri Cities- Benton Franklin Parent to Parent program sight visit. English and Spanish speaking program. Have a Project LAUNCH contract as well.

3. WSLI Leadership Steering Committee meeting-Evaluation and also Steering and Planning Committee meeting.

4. Promoting Middle Childhood Health Summit planning.

5. Parent to Parent Coordinator Training in Wenatchee
   a. DDA waiver information about how to bill Medicaid for P2P peer mentor and community engagement services follow-up meeting in November. Meredith is helping with this.
   b. OEO Education information especially writing IEP’s during transitions.
   c. DOH/CSHCN information and grant writing with Meredith and Michelle.
   d. F2F- ADA information as well as Mental Health; PAVE.
   e. Parent panel- on how to support a family when their child passes away.

6. King County is expanding their outreach to a variety of populations; will provide outreach in whichever manner that families need; event happening; see Flyer; the Monday before Thanksgiving

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**Family to Family Health Information Center (F2FHIC)**
Jill McCormick  
[www.familyvoicesofwashington.com](http://www.familyvoicesofwashington.com)

Jill McCormick was unable to attend.

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**Open Doors for Multicultural Families**
Ginger Kwan  
[www.multiculturalfamilies.org](http://www.multiculturalfamilies.org)

Ginger Kwan was unable to attend.

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**Office of Superintendent of Public Instruction (OSPI)**
Robin Fleming  
Program Supervisor for Coordinated School Health  
[healthyschools.ospi.k12.wa.us/waschool/](http://healthyschools.ospi.k12.wa.us/waschool/)
Neurodevelopmental Centers (NDCs) Update
Marianne Bastin, Good Samaritan Hospital, Children’s Therapy Unit

The NDCs met with HCA in August to address maintaining fee-for-service billing, adding billable services, and reviewing rates. HCA response was no to rate increases as per the request from the governor office; no to adding billable services, suggesting contracting with MCOs instead; and NDCs will be carved into managed care at some point in the future. HCA requested the NDCs work on a model that would meet their needs and deliver value to HCA. NDC directors began this discussion at their meeting on September 26th. NDCs provide significant cost savings to HCA already by raising significant funds to provide services not in the current billing instructions. Services provided by the Centers early in life reduce the need for services later. Providing outcome information will be important for the future.

NDCs will need to defend their programs once again to avoid budget cuts in the next biennium. Current contracts end in June 2017. It is possible that the contract may be opened to new applicants requiring reapplication of current centers unless grandfathered.

Boyer Children’s Clinic – Mike Stewart
Boyer Children’s Clinic is the largest provider of early intervention services in Seattle, and we have proudly been serving families throughout the Puget Sound region for nearly 75 years. Last year, in response to the ever-growing needs of our community, we made a bold move to deepen our impact in the community through expansion. I am very proud to share that in June, Boyer’s new satellite clinic opened in the Magnuson Park neighborhood. This second location not only offers easier access to the high-volume of North Seattle families, but also frees up space and provides additional access at our original Mountlake location for South Seattle families, particularly from underserved communities. The new site offers nearly identical early intervention services as our flagship location, and once at capacity, we will be able to care for an additional 120 young children and their families each year.

In conjunction with the expansion, in 2015 we also launched our first major Capital Campaign in over 20 years. This $1.1 million initiative not only involves the construction of our new site and support for expanding our programmatic offerings, but it also includes updating our current facility to create parity and consistency between the two locations. The response from our community has been remarkable, and to date the Campaign is 85% complete.

Last, but certainly not least, one of our greatest recent achievements is our continued commitment to ensuring that all children and families have access to Boyer’s high-quality programs and services, regardless of financial circumstances. We never turn families away due to lack of insurance coverage or an inability to pay, so our Uncompensated Care Program continues to be an important safety net for many in our community. Thanks to our generous donors, I am thrilled to report that over the last five years, Boyer has provided over $3 million in uncompensated care to uninsured, underinsured and low-income families.

Holly Ridge Center – Connie Zapp
Holly Ridge Center held several fundraisers over the summer, our Bright Beginnings Breakfast with guest Amy Roloff from Little People, Big World, was a great success. With having over $800,000 in uncompensated care in 2015, we could not survive as an agency without our fundraising and local support. Hiring new professional staff is always difficult, as nonprofit salaries do not compare to Hospital salaries and early intervention is a very specialized field, so we are very excited to be fully staffed as we start this “school year.” We have hired a new graduate OT and a full time PT with extensive pediatric experience from Oregon. Our ABA program is expanding and so we have hired two new Registered Behavior Technicians. It is exciting to have so many new and experienced staff, our issue now is facilities and not having space to put everyone!

Innovative Services NW – Susan Lehr
Innovative Services NW provides a diverse array of services for children and adults with developmental disabilities and delays. Early Learning and ECAEP, Adult Day Health services, Employment Services, Janitorial Services, Pediatric Therapy and Early Intervention, as well as Supervised Visitation are among the many programs we deliver helping people reach their greatest potential.
Innovative Services NW is growing with additional therapists to serve children in Early Intervention and Outpatient pediatric therapy.

Physical Therapist – Ali Walls, Speech Therapist – Bri Brown, and COTA – Melodie Sherer joined our team this summer. Additionally, we have a new Early Intervention Specialist – Emily Castor who has joined the team when another member left.

Innovative has begun offering free Photo optix vision screenings to all our clients. We look to expand our feeding clinic in 2017 as well as pursue BCBA services in 2018.

We are excited WAAA is expanding their service areas into SW Washington. Their new advocate will be starting very soon and will be based out of Innovative Services NW.

It has been extremely challenging to find therapy and educational staff to maintain and grow to meet the number of children with needs. Most recently, it took 6 months to find a physical therapist. We are fortunate to have capitalized on summer transitions to recruit new staff. However, now that school is back in session, we have not received any EIS applicants for an opening nor PT or PTA applications for a 2nd open position. Innovative has expanded their advertising reach and budget for recruitment as well as initiated direct hire contracts with staffing agencies. They too are finding it difficult to locate staff for temporary or full time employment. Special Education teachers are equally difficult to locate and hire. Teacher licensing is taking more than 2 months for the teacher’s license processing which delays our ability to get our newest team member up and running.

Therapists serving in schools require the ESA certification however there are only 3 classes a year to train new staff. My understanding is that there is one class per fall and spring held in the King County area. Additionally, there is one online summer course offered. As of August 15th, the October class was already booked. The next class will be in March 2017. This makes it exceptionally difficult for us to get our new staff the training they need. I would like to advocate for additional online class opportunities. If the infrastructure exists to offer online classes, it seems this could be provided at least quarterly to allow for year round hiring of staff to get their necessary training. Online also would save travel dollars and time allowing us to meet school requirements, and productivity needs to serve clients and families more efficiently.

We have an amazing team of therapists who are driven to strengthen children and families’ lives. Each day children and their family receive the therapy and supports they need to be stronger, more independent, and capable.

As the Director of Health Programs for about 1 year, I continue to learn the needs and opportunities Innovative has to serve our clients and families even better. I would welcome the chance to meet with other pediatric therapy directors to better understand best practices for managing and running a clinical setting as well as early intervention services.

Mary Bridge Children’s Therapy Services- Tacoma – Angela Kitzmiller

Audiology: Supporting MB ENT Clinic two days per week. Have added FTE and on-call position to help with number of patients we are seeing.

OT/PT/Speech: Telehealth Pilot-Amy McMillan, SLP received a grant to complete a telehealth pilot. Currently, serving three patients for Aural Habilitation. Will start to see feeding follow-up patients this quarter, including one in Alaska. Hired first physical therapy assistant. Hired Orthotist that will split time between Mary Bridge and CTU. Continue using our treatment pathways work to ensure we are seeing children at their optimal times for therapy and progress.

Maxillofacial Review Board: Currently providing case management to approximately 160 patients and families.

(Mary Bridge) Children’s Therapy Unit at Good Samaritan- Marianne Bastin

- We have added additional Speech therapist and COTA positions. Will be adding additional PTA position before the end of the year. Wait times for services are highly variable depending on family availability. 70% of patients are getting first appointments within 30 days of referral but wait lists continue to grow for all services.
- OT had added several new social skills groups including a teen group that has been well received with good outcomes.
- Constraint camp continues to provide short duration high intensive therapy for children with upper extremity involvement such as hemiplegia and brachial plexus injury. Mini camps (one day) and a bi-manual camp are also well attended and offer a “tune-up” and extended treatment respectively.
- Behavioral Health staff are expanding their ability to provide services to our patients in Tacoma so that families don’t have to travel so far for services.
- The Movement Lab will be running a pilot series of patient through gait analysis in preparation for offering these services on a regular basis in 2017.
• We piloted a transition clinic for adolescents moving from pediatric to adult care this summer. Patients left with a care plan and connections to adult providers. Parent feedback was overwhelming positive. Next steps include funding support for a full time clinic.

DEL has started a new Strengthening Families Washington (SFWA) August/September Newsletter! SFWA at the Department of Early Learning, in collaboration with several partners throughout the state, have come together to Engage, Connect and Inspire the prevention community. This bi-monthly newsletter will highlight national, state and local news and resources, tips and tools and inspire communities to continue doing the hard work of ensuring all families and children in our state have the opportunity to reach their full potential. If you would like to be added to our distribution list, please email strengtheningfamilies@del.wa.gov.

Kathy Grant-Davis has been promoted to the position of Assistant Administrator of Policy, Contracts and Compliance. Her new responsibilities include oversight of all activities relating to contracts, including supervision of ESIT’s contract manager. She will also be responsible for oversight of monitoring activities and will continue to serve as lead staff for policy and regulation development.

Debi Donelan has been promoted to the position of Assistant Administrator of Training and Technical Assistance. Her new responsibilities include oversight of all activities that relate to training and technical assistance, including supervision of ESIT’s program consultants. She will be responsible for statewide training and support activities including leading the State Systemic Improvement Plan (SSIP) and the state’s comprehensive system for personnel development (CSPD). Debi will also be responsible for leading quality improvement activities for service delivery based on standards for early intervention services.

We will soon be recruiting for a program consultant and are especially interested in applicants who have experience as early intervention providers in the state of Washington.

ESIT Data Activities: July through September was a compliance monitoring period during which ESIT program consultants worked with Local Lead Agencies (LLAs) to review data for compliance and accuracy. Beginning in October, program consultants will facilitate quarterly calls with LLAs for data coaching.

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 ESIT program. Over 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. A draft of the system redesign proposal will be shared at the October SICC meeting (details below). A webinar will be held on Friday, October 21, from 10:00-11:00 a.m. to share the proposal with those who cannot attend the SICC meeting. Register through this link: https://attendee.gotowebinar.com/register/1197743473933950722.

State Systemic Improvement Plan (SSIP) Update: We have moved into Phase III of SSIP. We have begun implementing statewide activities such as requiring early intervention providers to participate in training via Child Outcome Summary (COS) modules and developing a Memorandum of Understanding between ESIT and the DEL home visiting program that addresses referrals, teaming, service coordination, and data sharing. We are implementing focused training and technical assistance activities with LLAs and providers in four implementation sites: Columbia/Walla Walla, Island, Pierce, and Yakima. Providers have participated in Promoting First Relationships training and developed local implementation teams to share successes and challenges of implementation with ESIT.

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 9:00AM-12:30PM. 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 October 19 from 9:00-3:00 at the Wenatchee School District Board Room, 235 Sunset Avenue, Wenatchee, WA 98801. The focus of this meeting is family stories. Contact Jahla Brown at (360) 725-4413 or email Jahla.Brown@del.wa.gov for more information or to RSVP.

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**DSHS, Developmental Disabilities Administration (DDA)**

Nicole Fergason

Community First Choice waiver. Doing some WAC changes – assistive equipment being added; also adding iPads and tablets as well as “Apps”; will pay to repair some items; limits on some items; like 2 years.

What is the user training and parent support? Need to go back to the ordering provider for training.

Also using dollars to pay for some specialty household items like stoves that shut themselves off.

IFS – new waiver – individual family service waiver – for people who have been on a waiting list. Allotment of funds for services such as respite; working hard at getting more people on the waiver. (See Attachment #6)

Working on Advanced Home Care Aide Specialist Pilot Program for supporting caregivers and scheduling hours. (See Attachment #’s 7 and 8)

Will bring updates from other DDA program managers to Communication Network meetings.

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

Michelle Milholland-Fears

Continuing care coordination services for the FFS (fee for service) population. Increasing caseload especially non-citizen and Tribal youth. Voluntary placements also being supported by this programs.

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**DSHS, Kinship and Family Caregiver Program**

Hilarie Hauptman

[www.dshs.wa.gov/kinshipcare](http://www.dshs.wa.gov/kinshipcare)

Washington State’s Aging and Long Term Administration/DSHS’s Lifespan Respite Grant proposal submitted late Spring 2016 to the Administration for Community Living for an expansion of its existing three-year funded project was one of eight grants awarded to states. This one-year grant opportunity focuses primarily on the direct provision of respite services to fill identified gaps in service delivery and address unmet needs. Linda Porter, Lifespan Respite WA, Coordinator and Hilarie Hauptman, Kinship and Family Caregiver Program Manager will be working closely to support eight Tribes as they provide culturally relevant kinship respite services. Support for the grant with commitments to be able provide information and resources came from state headquarters staff from DSHS/Developmental Disabilities Administration, DOH/Children with Special Health Care Needs, and Department of Early Learning/Early Support for Infant and Toddlers.

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**Lifespan Respite Washington**

Linda Porter

[www.lifespanrespitewa.org](http://www.lifespanrespitewa.org)

Please let Linda know about any Respite program activities in your community.

Processing respite vouchers – all ages – for clients who need 40 hours a week of care or more and don’t have access to Respite through other systems such as DSHS-DDA.

Worked on a pilot project with DOH; $1,000 per child; will be starting up again in January. Lots of lessons learned.

Respite coalition meeting on Monday, October 17; if you want to participate, please contact Linda.
Presented the DOH pilot at a recent national conference.

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

WithinReach’s Family Health Hotline and website, Parenthelp123.org, serve as Washington State’s Shared Resource under the Great LINCS project. Through this grant we have been able to expand our capacity as a database and navigation service to support providers and families with 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 and engagement opportunities for families and partners. Let us know if you are interested in learning more! 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, and Family Support Coordinator, Jen St. Cyr, began working with the University of Washington Bothell’s Data Visualization course this month to further explore how and when families are engaging in resource search/access so that we can better support them and improve outreach and communications strategies. This research project will span the school year, beginning with a national lens and then wrapping up with state and regional focus. This partnership has been with our Immunization team in the past, with fantastic results and very useful visual data that we continue to use. The Child Development and Special Health team are excited to engage in this new opportunity!

Maggie Kizer, Bilingual Child Development Specialist, is attending this month’s Great MINDS training in San Juan County to demonstrate our ASQ follow up process and comprehensive resource assistance using the Resource Finder on Parenthelp123.org.

Immunizations

The immunization team at WithinReach is using its well-honed event planning skills on a new endeavor. On April 26, 2017, we will host the first ever (and hopefully annual) Washington State Immunization Summit at the SeaTac Conference Center. Guided by best practices nationally, we have decided to offer an annual summit for immunization stakeholders from any sector across the state. Continuing education credits may be available (see website for details). Washington leads the country in the immunization field in many ways (our hesitancy research, our cutting-edge HPV work, etc.), and this is yet another way that we want to support our state in taking the lead. In creating this summit, our goal is to offer responsive, cutting-edge immunization education to our partners. You can learn more and register today. Please spread the word widely.

AmeriCorps Outreach and Enrollment Team

September 1st marked the first day of our new AmeriCorps team! This cohort will be part of WithinReach’s Outreach and Enrollment team in King and Snohomish Counties for the next 10 months. Our AmeriCorps members go in person to food banks, libraries and job centers and truly make the connections our families need to be healthy. With iPads in hand, this year’s team of 8 will have the ability to enroll individuals and families in health insurance, food benefits and reduced-fare bus passes on the spot, as well as share information about our Child Development program and special needs resources and support. A core value of our outreach model is to meet our clients where they are —whether that means standing in line at a food bank when the temperature reaches freezing, or spending a hot summer afternoon at a local library in order to ensure that a family has the resources they need to meet their nutritional needs.

Liv Woodstrom was unable to attend.
Looking for a Secretary Senior as well as a new Genetics staff member.

25% of funds are dedicated for family engagement; developing a family advisory committee; family training also.

In 2014, Legislature passed a rule about performance based payment; this past year, added some pediatric measures; a webinar to happen soon.

UDS data system – completed work with vendor; review this afternoon about documentation and business requirements depending on audience; presenting information on October 17.

Down Syndrome pamphlets are now available. Encouraged to share these resources with community partners. See Attachment #9 for Resources for Families Who Have a Member with Down Syndrome Flyer and you can find more information regarding the pamphlet on Screening and Genetics Unit website http://www.doh.wa.gov/YouandYourFamily/InfantsChildrenandTeens/HealthandSafety/GeneticServices.

The Central Region met via conference call September 14th. See Attachment #10 for the region meeting minutes. Central Region’s next meeting is December 14th via conference call.

The Northwest Region met September 20th at Snohomish County Public Health in Everett. See Attachment #12 for the region meeting minutes. Northwest Region’s next meeting is October 26th in Coupeville.

The Southwest Region met August 25th at Department of Health in Tumwater. See Attachment #12 for the region meeting minutes. Southwest Region’s next meeting is scheduled for November 17th at Department of Health in Tumwater.

The East Region met August 11th at Spokane Regional Health District in Spokane. See Attachment #13 for the region meeting minutes. East Region’s next meeting is November 10th at Spokane Regional Health District in Spokane.
Special Presentation

PRISM (Predictive Risk Intelligence System)
Using the PRISM List Capability
Ellen Silverman and Colette Jones

This presentation provides an overview the definition of CSHCN and WA state CYSHNC data as well as how the CHIF data intersects with Medicaid. Additionally, enhancements to the PRISM system to identify children with special health care needs will be discussed in order to facilitate care coordination and improved quality of care by Medicaid MCOs. Attendees will participate in a brainstorming process for ideas on how to approach the PRISM system enhancement. (See Attachment #14 for PPT slides.)

Announcements

1. DDA has just made requesting services a lot easier with its new online Service Information & Request form. This is a great opportunity for individuals on DDA's No Paid Services (NPS) caseload to take advantage of open enrollment on the Individual & Family Services waiver and other services.

   If you or your family member would like more information about what's available, or would like to request specific services if you are already a client of DDA, fill out the easy to use online form and someone from your regional DDA office will get back to you.

2. ThinkGenetic. ThinkGenetic is a free new online resource for patients living with a genetic disease or who need to determine if their medical condition is a genetic disease. The content is 100% curated, referenced and accurate having been through a four level review process of genetic counselor, editor, subject matter expert and patient or patient advocacy group review. It’s ideal for medical students who are learning about the genetic conditions that they are likely to be asked about. The content knowledge currently covers 150 of the genetic diseases most asked about. Over 100 genetic counselors are involved in content creation, with 250 diseases covered within a month and more added weekly. ThinkGenetic is the result of a collaboration between ThinkGenetic, Inc., the Emory University Department of Human Genetics, and IBM Watson Healthcare. Visit https://www.thinkgenetic.com.

3. Shanne Montague, the Middle Childhood Health Consultant at the DOH, has coordinated two meetings to discuss concerns about the lack of resources and supports for children that fall within the Middle Childhood age range. The first meeting was on…. And the second meeting was on September 28, 2016. If you are interested in participating in this quarterly meeting contact Shanne Montague at shanne.montague@doh.wa.gov or 360-236-3560.

   Shanne Montague is coordinating a Middle Childhood Health Summit in the fall of 2017. The initial planning meeting will be on October 17th in Kent, Washington. If you are interested in participating in this summit or the planning please contact Shanne Montague at shanne.montague@doh.wa.gov or 360-236-3560.

4. Upcoming Webinar Series: Maximizing Insurance Enrollment in MCH

   In partnership with Family Voices, AMCHP is hosting a three-part webinar series on outreach and enrollment. The series, "Maximizing Insurance Enrollment in MCH," will feature presentations from MCHB, CCIIO, Enroll America, state advocates, and health insurance navigators from the family leader community. You can register for one or all of the webinars at the following links:

   Thursday, October 13th – 1:00-2:30 PM eastern
   Strategies to Connect with Adolescents and Young Adults

   Tuesday, October 25th – 2:00-3:30 PM eastern
   Strategies to Enroll Hard-to-Reach Populations

   Wednesday, November 9th – 3:00-4:30 PM eastern
   Strategies to Address Challenging Enrollment Situations

   For more information, contact Emily Eckert at eckert@amchp.org.

Back to top
Attachments

1. Healthy Starts and Transitions PowerPoint Slides
3. UnitedHealthcare Children’s Foundation Flyer
4. Medical Home Leadership Network and Community Asset Mapping Coalitions
5. Child Health Notes – Red Flags in Speech and Language Development
6. The IFS Waiver is Enrolling Now Flyer
7. Advanced Home Care Aide Specialist Pilot Program Flyer
8. Advanced Home Care Aide Specialist Pilot Program Discussion Guide
9. Resources For Families Who Have A Member With Down Syndrome
10. Central CSHCN Region Minutes
11. Northwest CSHCN Region Minutes
12. Southwest CSHCN Region Minutes
13. East CSHCN Region Minutes
14. PRISM(Predictive Risk Intelligence System), Using the PRISM List Capability PowerPoint Slides
15. 2017 CSHCN Communication Network Meeting Dates – MARK YOUR CALENDARS

Next CSHCN Communication Network Meeting
Thursday, January 12, 2017
Creekside Two at Centerpoint
20425 72nd Avenue South
Kent, Washington
Conference Room 309