

CHILDREN WITH SPECIAL HEALTH CARE NEEDS  
NORTHWEST WASHINGTON REGIONAL MEETING  
6/30/16

10:00 – 2:00

Snohomish Health District Auditorium, 3020 Rucker Ave, Everett

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**Meeting notes:**

**Round Table:** King P2P working on building supports for dads—one way is a private Facebook group. Island P2P bringing Sibshops to Island Co. Also working w/Father's Network. Planning a sensory event at local movie theater. Snohomish P2P welcome to new staff member Melissa! Creating a toolkit for adult sibling support. Kitsap CSHCN has scheduled Emergency Preparedness training with CSHCN in mind for 9/2017! DOH excited about new work plans—webinar next week. Island CSHCN experienced death of a CSHCN child—a difficult and growth experience. Snohomish CSHCN—caseload polarized between high needs families and referrals doing OK without CSHCN service. Lifespan Respite—excited about new contract with DOH.

**Lifespan Respite WA**—Linda Porter led discussion re: Respite needs, situations, and new process through Lifespan Respite WA working w/DOH for CSHCN. Respite providers must be paid through an agency, not as individuals, even if family members.

**DOH updates**—Chris Zipperer brought Bright Futures—Oral Health booklets and Autism Tipsheets from Readilab. Provided information re: SNAP's food insecurity nutrition incentives at Farmers Markets, Community Health Clinics, and Safeway. October 18<sup>th</sup> is the DOH led MCHBG NW Region meeting in Coupeville.

**Coping with death of child**—discussion about providing support to families while maintaining personal mental health. Trauma Stewardship a resource (see addendum). Be patient with ourselves during time of grief/loss. Share grief outward—not in toward family.

**Special Meeting of the NW Region**—Change in September Regional meeting: Parent Panel to talk about support—what parents want and what they do not want. King P2P staff to address cultural issues faced by parents—Spanish, Vietnamese, Somalian, and African American. Other cultures also of interest: Marshallese and Filipino. Invitations will be sent to a somewhat broader audience.

**Addendum** re: Resources discussed in meeting (thank-you Jennifer!):

- <http://www.nurturingexpressions.com/> for baby scale rentals
- <http://www.drhallowell.com/> for lots of free ADHD information
- Compassion Fatigue resources:
  - *What about You? A Workbook for Those Who Work with Others*. The National Center on Family Homelessness. <http://508.center4si.com/SelfCareforCareGivers.pdf>
  - Ted Talk on Compassion Fatigue <http://tedxtalks.ted.com/video/Beyond-the-Cliff-Laura-van-De-2>

**Upcoming NW Region Meetings:** 10:00 – 2:00 (NOTE revised meeting dates not yet determined)

- ✓ 9/20 OR 27 Special meeting of the NW Region—P2P re: parent support/cultural issues  
Snohomish Health District auditorium, Everett
- ✓ 11/?? NW Region Meeting in Coupeville

#### **COUNTY UPDATES:**

**Clallam:** Caseload remains around the same. Clallam County will be hiring a new nurse this month who will be involved with CSHCN Program, I am hoping she will attend our next meeting. Transportation issues seem to be improving around the county.

**Island:** having a spate of premies (36 weekers) now. Experienced the death of a child. Continuing to enroll kiddos when they are referred or I come across them.

#### **King:**

- 3.5 PHNs provide CSHCN Case Management in King County. Currently working to fill two .5 PHN positions within our workforce to serve CSHCN families. This would give us 3 full time PHNs and 3 part-time PHNs to serve our special needs kids in King County.
- Working to build relationships with community members and organizations. Doing this by attending meeting such as the King County Interagency Coordinating Council (KCICC).
- Continued to participate in the newly forming Smooth Way Home Group, a collaborative working to improve the transition for CSHCN discharging from the NICU to home. The group continues to define their role in this process. We are currently focusing on the emotional support needed during the NICU stay and the initial homecoming. Cooper House, an organization specializing in Infant Mental Health, is starting a pilot to assist caregivers with emotional support during this time. The longer term vision is to train others who work with this population such as Public Health Nurses to give this emotional support.
- Participated in another meeting discussing transitioning from NICUs. The Supporting Fragile Infant Feeding and Nutrition from Hospital to Home meeting took place in Kent and consisted of various disciplines (RN, MD, RD, OT, etc.) mostly from the Seattle area along with DOH staff and UW staff. They were also lucky to have a few vocal and informative parents present. The meeting highlighted issues that providers and patients are having around feeding issues during the NICU discharge/early home stay timeframe. I hope to have the meeting minutes soon to see what's planned for next steps.
- The CSHCN PHNs are attending a Tube Feeding Training put on by Seattle Children's Outreach department. This is intended to increase our knowledge of current tube feeding practices. Although our nurses will not be doing hands on work with the tubes, having this knowledge will better help the PHNs provide consistent and accurate information to the many families we serve with both NG and G tubes.

**Kitsap:** Update of the Contact Database Provider list completed, along with set-up of email template and list for 1<sup>st</sup> electronic CHN send out set for Early Fall; copy of new ACE CHN routed to State MHLN

coordinator. Recent trainings: ASQ-3 & ASQ-SE. Cardiac Heart Defects In-service for KPHD PCH staff scheduled. New Kitsap P2P Coordinator: Melissa Lund. Invite sent out to FICC members re: 2 day Pediatric Disaster Response & Emergency Preparedness course via FEMA; scheduled for September 2017.

#### **San Juan: CYSHCN**

- The SafeCare Home Visiting Program is in place each of the three most populated islands and services are going well.
- First Year Family Resource Coordinator Training continues for our Community Health Services RD who is covering ESIT FRC services for San Juan Island.
- Our new School Nurse will begin CYSHCN training in July, to enter CHIF data and begin serving families on San Juan Island.
- Outreach efforts have begun with a one page ESIT referral form, included with the state required forms, to promote ease of referral. Follow up phone calls and visits to Providers will continue over the summer months.
- ACES screening continues through Maternity Support Services, with resiliency information promotion, as well as mental health service referrals.
- Lead screening was completed for Head Start with no child showing high lead blood levels.
- Washington State School for the Blind (WSSB) has come to the county to promote Teacher of the Visually Impaired (TVI) services for two children.
- Due to budgetary constraints, our CSHCN Coordinator will not be participating in the June 30<sup>th</sup> meeting. She will attend the Sept. 29<sup>th</sup> meeting in Coupeville to couple it with another “out of county” training on September 30<sup>th</sup>, to save travel expenses.

#### **Skagit:**

- P2P offered 55+ events and during the 2015-16 contract year. We also collaborated with multiple agencies and programs on additional events for parents of children with special health care needs and/or developmental disabilities. We'll be offering numerous no-host community inclusive events during the summer months and gearing up for a new school year packed with rich opportunities.
- CSHCN: Our Skagit Multidisciplinary Autism Review Team (SMART) piloted the evaluation process recently and it worked rather well. The Skagit County Autism Partnership (SCAP) group is reviewing the process to tweak it a bit to make things a little smoother. Emily, our Community Health Worker, is functioning as the intake/coordination person for families.
- Working with child care sites on supporting them in their care of CSHCN. Also working on a clearer process for them to utilize Help Me Grow to get children in their care screened and get the results of that screening along with the families.
- We will be contracting soon for an early childhood behavioral health specialist to work with local child care providers and the children/families they serve.
- Our United Way has decided to make Early Learning a signature focus for this coming year, and we are working with them on strategies for services, communication, metrics, etc.

**Snohomish:** Participated in local Community Asset Mapping for Universal Developmental Screening to develop plan for next steps. Drafted questions and identified providers to interview re: use of ASQ/ASQ-SE within healthcare settings. Identified need for accessible mental health supports to teens residing in homeless shelter—updated resource list specifically for teens. Arc of Snohomish County Parent to Parent has a new staff member (Melissa Reyling).

**Whatcom:** As CSHCN Coordinator, my focus is to work with community partners in Whatcom Taking Action to improve our local system of care for CYSHCN. Whatcom Taking Action updates:

- We've been working to secure an administrative home and location for Whatcom Taking Action's General Interdisciplinary Developmental Evaluation System (GIDES), and we're happy to report that Unity Care Northwest has agreed to partner with us! We will be meeting with them to work out details.
- Monica Burke and I attended in the Help Me Grow National Forum in South Carolina last month. We were asked to participate in a break-out session panel to talk about our Mid-Level Developmental Assessment project. (GIDES) We came away with many wonderful resources.

- Whatcom Taking Action had a technical assistance site visit from National AAP and MCHB Healthy Tomorrows grantors. It was a productive day, with a total of 61 people in attendance throughout the day.
- In year two of the grant period, we will be working to increase developmental screening of young children in Whatcom County. To that end, we have partnered with a pediatrician to discuss developmental screening with a non-pediatric family practice group. We plan to contact other primary care practices to offer this consultation. We are also in discussions with smaller county school districts to explore how we, in Taking Action, can assist in ChildFind efforts.
- Our Family Tools Team continues to develop informational handouts and tools for families which we post on our Taking Action website at [www.whatcomtakingaction.org](http://www.whatcomtakingaction.org).
- We have two new full time interns working Whatcom Taking Action for the summer. Paige, placed at the Whatcom County Health Department, is a senior in the Community Health Program at WWU, and she will be focusing on obtaining and producing family stories to help illustrate particular needs and issues that families face. Desi, placed at The Arc of Whatcom County, will be working as an administrative assistant for GIDES this summer.
- We have been able to use Diagnostic and Treatment funds for 3 children to attend FACES Northwest, a local summer camp for children with autism.