

URLEND Alaska Exchange

Day 1: ANMC Genetics Outreach Clinic

Starting my week in Alaska

I am excited to be spending a week in Alaska, visiting clinics as a LEND trainee. I am hoping to learn more about the healthcare challenges families face in this region.

Genetics Outreach Clinic

Today I observed at the genetics outreach clinic at Alaska Native Medical Center (ANMC). At the clinic I met Dr. Jon Zonana (medical geneticist) and Kory Keller (genetic counselor) from Oregon Health Science University. Anke Kelley, a genetic counselor from ANMC, was also seeing patients at this clinic.

I learned that the genetics outreach clinic is held two times a year at ANMC and every other month at Providence Medical Center. The prior two days Dr. Zonana, Kory and Anke were seeing patients at the genetics outreach clinic at Providence Medical Center. This was the third and final day of this month's clinic. Oregon Health Science University is contracted with the state of Alaska to staff the genetics outreach clinics at Providence and ANMC. Prior to their contract, the clinics were staffed by Seattle Children's Hospital.

Patients are referred to the clinics by their primary health care provider. They may be scheduled at either Providence or ANMC. The funding source at ANMC is the Indian Health Services (IHS). Patients at Providence may be funded by IHS, Medicaid or other private insurance companies.

Today I observed consultations with four families. I recognized some of the challenges they faced including travelling long distances. One family travelled an entire day prior to the consultation from a remote village in the Yukon-Kuskokwim region. I also recognized a lack of adherence to medical recommendations for testing, follow-up appointments and medication. I think this could be due to difficulties accessing medical care in rural communities. I also sensed that there could be a cultural disconnect between the patients and the healthcare providers that creates additional barriers. In this setting, patient-centered care seems to be especially important to create a healthcare plan that will work in the context of the Native culture.



*Alaska Native Medical Center in Anchorage
(Image: anthc.org)*

Unique Genetic Challenges

Certain autosomal recessive genetic conditions are more common in this region. Because many families live in rural villages, there is a higher likelihood for consanguinity among parents. This increases the likelihood of recessive genetic conditions.

There are unique and rare genetic conditions that are more prevalent in this region. For example, there is a form of arthrogyriposis that is seen in newborns which is thought to be caused by a gene inherited in an autosomal recessive pattern. The research has not been done to identify the gene associated with this condition. This is partially because there are many challenges associated with initiating genetic research in populations living in rural, remote areas of Alaska.



*The Primary Care Center building at ANMC
where the genetics outreach clinic is held*

March 21, 2014
Anchorage, Alaska

Day 2: Alaska URLEND Program



The LEND group from Anchorage, AK

A day to learn about LEND

Jeremy John and I met Jenny Miller this morning to learn about the LEND program in Alaska. Jenny is the Training Director for the Alaska LEND program. She is also a professor in the public health department at the University of Alaska. We discussed some of the challenges in healthcare in this region and some of the unique programs that are available.

The Alaska LEND program began four years ago. They have a similar model for video distance learning as our URLEND program. The trainees from Anchorage meet together at the Center for Human Development (CHD). Trainees also join by video conference from other sites. This year there are trainees in Fairbanks and Sitka.

The Center for Human Development (CHD)

The CHD is the University Center for Excellence in Developmental Disabilities (UCEDD) for the University of Alaska. Programs for community training, research and interdisciplinary education are housed at the CHD.

Jenny told us about a unique program run by the CHD called "Friendships and Dating". This is a program for individuals with intellectual disabilities to learn skills to establish healthy friendships and dating experiences.

Alaska LEND Seminar

Jeremy and I were able to attend the LEND seminar this afternoon. Richard Kiefer-O'Donnell, an associate director at the CHD, facilitated a panel about the Complex Behavioral Collaborative (CBC) and the Early Intensive Behavioral Intervention (EIBI). Professionals working in this field talked about the process of providing education and training for behavioral interventions. The individuals from the panels work with the caretakers of individuals with significant behavioral challenges to provide education for effective interventions. I thought that this program is a unique solution to the difficulties of providing interventions and assistance in rural communities.

Carrie Plant, from Barrow, Alaska, talked about techniques for accessing Native networks in the state. With so many rural communities, it can be difficult to inform individuals about local programs. Carrie discussed the effectiveness of several strategies including working with tribal councils, having a local champion for the program, and using radio, fax and text communication for dissemination of information.

One of the LEND trainees, Jess, talked about her recent experience observing at a clinic in Homer Alaska.

**March 21, 2014
Anchorage, Alaska**

Day 3: Providence Medical Center

Child Life Center

On my last day in Anchorage I met Jen Booher at the Child Life Center at Providence Medical Center. Jen is a Child Life Specialist at Providence and works primarily with oncology. I learned that Providence has a strong Family Support Services department with four Child Life Specialists and multiple Family Navigators. This department is funded by grants and philanthropy to provide this support to families.

Child Life Specialists provide education, play time and distraction for children at the hospital. Jen says that she will educate the children she works with about their diagnosis and help them know what to expect when they prepare for surgery or treatments. I was able to observe Jen providing play and distraction for a young child receiving a chemotherapy treatment. When the medical care provider was accessing his port, Jen helped him by blowing bubbles and showing him the TV to keep him occupied.

I also was able to sit with one of the Family Navigators while she talked with a mother of a child who was near the end of her successful cancer treatment. Family Navigators help parents access support services and programs while they are receiving care at Providence.



*Providence Medical Center, Anchorage
(Image: www.alaska-in-pictures.com)*



Visiting Providence Medical Center

Pediatric Neurodevelopmental Clinic

In the afternoon I met with Megan Bolthouse. Megan is a LEND fellow who works at Providence as an occupational therapist. She provides both inpatient and outpatient services, though her priority lies with inpatient needs. There is a long waitlist for children to receive occupational therapy or speech therapy at Providence. This is a consistent problem throughout the state and is due in part to the lack of providers in the state and lack of funding. There is a triage system for processing the wait list to try to schedule the most urgent children first.

I was able to observe an outpatient evaluation of a 6 month old baby. I was also able to observe Megan work with a teenager who was inpatient after a recent surgery to stabilize fractures from a fall.

**March 21, 2014
Anchorage, Alaska**

Day 4: Psych, SLP and OT in Fairbanks



The ACCA Community Center where I met Gretchen for her FACES evaluation

Fairbanks, Alaska

Last night I traveled to Fairbanks to spend my last two days learning about the support services available in areas outside of Anchorage. I am able to enjoy the beautiful scenery while meeting with past and current LEND fellow in Fairbanks.

Thrivalaska Head Start

I met Jeanine Jeffers-Woolf at Thrivalaska Head Start. Jeanine is a current LEND fellow and is an early childhood mental health psychology consultant for Thrivalaska Head Start.

I was able to meet with her at the Head Start office and observe an administrative meeting reviewing the progress and challenges of the children currently enrolled in the program. There is a higher incidence of childhood trauma in Alaska and during the meeting it was clear that there was a focus on both education and family life. The staff was concerned with both the child's cognitive progress as well as social and emotional needs.

**March 25, 2014
Fairbanks, Alaska**

Community Meeting

I was able to attend an early childhood development community systems concerns meeting. Several psychologists, therapists and social workers meet monthly to identify ways to improve the Fairbanks system for childhood development. Today they were learning about a tool for evaluation of parent-child interactions. I was impressed with the sense of community and collaboration between professionals within this field.

Meeting with Betsy

After following Jeanine, I was able to meet with Betsy Jacobs. Betsy is a speech therapist and was a LEND fellow in 2011. Betsy has a private practice and consults with the Alaska Center for Children and Adults (ACCA). The ACCA provides the Infant Learning Program (ILP) services to children in the Fairbanks region. The ACCA uses a coaching early intervention strategy for the ILP. For example, Betsy will make home visits for speech therapy and teaches the family how to incorporate speech therapy into their daily life. She has found this method of service delivery much more effective than the traditional methods.

Betsy also organized a grassroots effort to have a summer camp for children of all abilities in Fairbanks last summer. She will be running the camp again this year. Betsy also trains service dogs and I was able to meet one of the dogs she is currently training.

FACES

I observed Gretchen, an occupational therapist from the ACCA. She was conducting an evaluation for the FACES program. FACES (Fairbanks Area Community Evaluations Services) is an interdisciplinary team in Fairbanks that provides evaluations for children with Fetal Alcohol Spectrum Disorder. The team includes several providers including a pediatrician, OT and psychology. Each team conducts evaluations and writes a report of their findings and they meet together to make recommendations for services. The family Gretchen was working with travelled from Nome, Alaska to have the evaluation. They expressed frustration with their difficulties in receiving services for their child and were hoping that this evaluation would help them receive necessary resources.

Day 5: Last Day in Fairbanks

Tanana Chiefs Conference (TCC)

This morning I was able to meet with Gina Pope, a Child Life Specialist working for the TCC. Gina travels to the villages surrounding Fairbanks to provide services and evaluations for the Infant Learning Program (ILP). The ACCA is contracted to provide services in Fairbanks, and the TCC is contracted to provide services to the surrounding areas.

There are 12 to 24 children that are receiving ILP services through the TCC at any given time. Gina travels to each child's home every three months. Children living in Fairbanks may receive more frequent services from the ACCA, but due to travel constraints, families in the surrounding regions receive visits quarterly. Gina visits one to two homes per week. It may take an entire day of travel to reach some villages because of the necessary connecting flights.

Family Perspective

I talked by phone with a mother, Caroline, who has a child with a genetic condition. Her son is now four years old and was diagnosed with significant hearing loss shortly after birth from his newborn hearing screening. She attended the genetics outreach clinic shortly after birth and again around 18 months after they noticed developmental delay. Based on her research she was concerned for Usher syndrome and requested genetic testing. Her son was found to have one known mutation and one variant of uncertain significance. Further testing with ophthalmology allowed a clinical diagnosis of Usher syndrome and the variant was reclassified as a deleterious mutation.

Caroline expressed some challenges she faced as she pursued a diagnosis for her son. She felt disconnected from the geneticist she met with at the outreach clinic. She wanted to have more support and guidance through the process. She was limited in the providers that were available and it took great effort and persistence to follow through with testing and receive a diagnosis. She believes that many families may receive a genetic diagnosis much later in life or not at all because of the challenge of access in many parts of Alaska.



The TCC is located at the Chief Peter John tribal building

Multidisciplinary Meeting

I attended an ILP multidisciplinary meeting at the ACCA. Providers with a background in special education, speech therapy, occupational therapy and psychology make up their interdisciplinary team. At this meeting they reviewed their new referrals and children requiring follow-up to ensure that they were receiving adequate services.

A major challenge to the ILP system is that children must have a 50% delay to be qualified for services through the state. The providers at this meeting expressed concerns about this because there are many children that would benefit from their services but are not eligible even though they have significant delays, but not 50% delay and they are referred to community services.



**March 26, 2014
Fairbanks, Alaska**

Final Thoughts about Alaska

Rural Alaska

I have learned a lot this past week about healthcare in Alaska. There seemed to be common themes across various disciplines related to some of the challenges for providing services in rural areas. Consistent staffing is a major challenge in rural locations and important specialized positions can remain unstaffed for months or even years.

I have been impressed with the creative solutions that have been used to solve some of the challenges associated with working in rural locations. Coaching early intervention and behavioral interventions empower parents and home care providers to resolve challenges that may otherwise need intensive therapy. The healthcare providers and specialists I met with seemed to really take pride in their work and actively advocate for better practice methods.

Native Culture

I loved learning more about the Alaska Native culture. It seemed that the most effective non-Native providers were the ones that worked the hardest to understand the culture. They were able to consider interventions in the context of the culture and family life.

There were challenges that seemed to arise with specialists from outside Alaska that were contracted to provide care once or twice a year. Although this may be the best solution at this time, there seemed to be a greater dissonance between the providers and the patients. This really highlights the importance of cultural awareness among healthcare providers.

Unique Challenges and Solutions

I have learned about patient-centered care during my experiences this year with URLEND. This experience in Alaska has allowed me to more clearly understand why one-size-fits-all healthcare doesn't always work. I have learned that unique cultures require unique solutions for healthcare. The status quo is not always the best way to get the job done and it takes people willing to advocate for change to improve the system.



Driving down the Turnagain Arm on the Seward Highway with my mom and sister

Beautiful Alaska

My parents and my sister were able to meet me in Anchorage and I was able to visit some of the beautiful sites of the area with them. We took a drive down Seward Highway and visited the Alaska Wildlife Conservation Center. This was an impressive home for many rescued animals native to the region. We also drove to the small port town of Whittier and walked on some of the snow-covered trails to catch sight of the glaciers in the area.



Moose at the Alaska Wildlife Conservation Center