The Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) program is an interdisciplinary learning experience for post-graduate trainees who want to learn to provide optimal services for children and adolescents with special health care needs and their families. The program connects trainees in Utah, Idaho, Montana, Wyoming and North Dakota using state-of-the-art technology for classroom, leadership, and clinical learning experiences.

According to Vicki Simonsmeier, a URLEND core faculty member, trainees are grouped into teams of diverse backgrounds to work on a variety of projects with the goal of building communication, leadership and advocacy skills. "They work on things that the U.S. Department of Maternal and Child Health have said are important," Simonsmeier said. "The projects must be of a high enough quality to result in a publishable paper, a presentation at a national conference, advocacy or legislation—some sort of product of high merit."

Trainees work across time zones to meet synchronously using distance technology. At the end of the year, they will make a presentation to their peers, and their research papers will be archived on the URLEND web site (www.urlend.org).

Individuals are encouraged to apply to the program in March and April every year. "We are looking for trainees in their end degree programs—advanced students or working professionals," Simonsmeier said. Additional information can be found on the web site.

### The projects

#### Characterization and Transition of Children with Autism Spectrum Disorder Served in a Specialized Preschool Program

Trainees involved in this project include Taylor Stevenson (Audiology, Salt Lake City), Ann Douglass (Psychology, Montana), Ana Caballero (Audiology, Logan), Laura Ambrose (Psychology, Montana) and Jamie Easler (Marriage and Family Therapy, Provo).

The goals of the project are to characterize children with ASD served in The Children's Center and to facilitate the transition from The Children's Center to the Neurobehavior HOME Program for eligible children with neurodevelopmental disabilities. Expected deliverables include publication (poster and article) and recommendations to The Children's Center for transition processes.

#### Early Identification of ASD—Year 2 of multi-year project

Trainees involved in this project include Molly Reidy (Physical Therapy, Salt Lake City), Carrie Guy (Genetics, Wyoming), Bradley Robinson (Pediatric Dentistry, Salt Lake City and Sydney Iverson (Psychology, Idaho).

This project is a continuation of a leadership project that created the Utah Network for Early Autism Response, which joined together multiple state agencies, advocacy groups, universities and community organizations to sponsor a series of statewide workshops with the aim of earlier identification of autism spectrum disorder.

The network created in 2014-2015 can be used to expand training and expertise in evidence-based intervention to the same or similar audiences. This project would develop sources of continued funding for the workshops. Products will include a qualitative article about follow-up needs and experiences and submitted grant applications for continuation of the project.
Campus Police Training: To Protect and Serve Inclusive Learning Communities

Trainees involved in this project include Mamie Thompson (Psychology, Salt Lake City), Ellie Pritchard (Health Care Administration/Nursing, Salt Lake City), Jeanna Floreani (Audiology, Salt Lake City), Lindsey Shankle (Public Health, Montana) and Holly Pedersen (Special Education/Hard of Hearing, North Dakota).

With the growth in the number of students with disabilities pursuing post-secondary education options on college campuses, there is obviously the potential for contact with campus law enforcement. Data suggests that the likelihood of engagement with law enforcement is higher for people with disabilities, and that those with “invisible” disabilities might be at greater risk of being misunderstood by inadequately trained law enforcement.

Effective and safe police response to individuals with disabilities requires both information to reduce misunderstanding and stigmatization, and the skills to make safe and appropriate decisions in potentially tense campus encounters. In response to this need, URLEND trainees will develop an in-service training curriculum designed to assist campus police to make safe and appropriate decisions when involved with students with disabilities.

University Faculty and Staff: Knowledge and Understanding of Neurodevelopmental Disorders

Trainees involved in this project include Nelson Atehortua (Public Health, Salt Lake City), Jamie Hammer (Nursing, Minot, ND), Katie Ahlers (Psychology, Montana), Ron Bean (Psychology, Logan) and Howard Fulk (Education, Moscow, ID).

This project will examine university faculty and staff members’ understanding of students who are on the autism spectrum, with the goals of identifying areas of strengths and weakness in individuals’ knowledge of working with students who are on the autism spectrum, and identifying areas in which faculty and staff could use support to increase their efficacy in working with students with ASD.

The project should result in a publishable journal article and the possibility of a conference poster presentation. It could also result in a short video presentation in effective communication skills when working with individuals with ASD, ideas for using strengths and ways for avoiding conflict.

Evaluation of Seclusion and Restraint Practices and Acceptability in Utah Public Schools

Trainees involved in this project include Tianna Freema (Psychology, Provo), Robert Kagabo (Social Work, Salt Lake City), Dusty House (Parent Trainee, Salt Lake City) and Anna Brady (Education, Logan).

Behavior management and student safety are important issues in our schools. Although educators and other professionals are moving toward greater emphasis on preventive interventions, those are not always effective. Therefore teachers must still be equipped to address disruptive problem behavior when it occurs. Seclusion and restraint are two such practices, however, recent legal cases regarding the ethics of using these practices, especially with minors, have gained the interest of policy makers and others. Despite the increased interest, few studies have investigated parents’ and teachers’ attitudes towards and beliefs regarding the use of seclusion and restraint with students with disabilities.

Cytomegalovirus (CMV) Public Service Announcements in Spanish

Trainees involved in this project include Canyon Hardesty (Public Health, Laramie, WY), Gisselle Warren (Audiology, Salt Lake City), Brittany Bown (Audiology, Logan), Kalie Moore (Audiology, Salt Lake City) and Anita Zambrano (Medical, Logan).

Trainees in 2014-2015 completed a Cytomegalovirus (CMV) Public Service Announcements leadership project that resulted in the creation of three PSAs of varying lengths, which are now widely available. These PSAs were completed in English and this project would expand its circle of influence to the Latino population by creating them in Spanish. The current trainees will become very familiar with CMV and its risks during pregnancy, and will research best practices for creating culturally competent messages to the Latino community by working with the Expecting Mothers group at South Main Clinic. A PSA will then be created/produced/filmed in Spanish to be distributed via social media and electronic outlets.

Spanish/English radio novella
Trainees involved in this project include Victoria Reyes (Audiology, Logan), Kathleen Lancaster (Social Work, Laramie, WY), Laurie Bowen (Special Education, Provo) and Lourdes Flores (Family & Consumer Sciences, Salt Lake City).

Culture plays a large role in parents’ expectations regarding developmental milestones. Racial and ethnic diversity is growing dramatically in the United States, especially at younger ages. Also at present, there is a significant health and disability disparity gap among racial and ethnic groups. The need for accessible health care information, nuanced for children with special health care needs, and those with decreased access due to rural locations, poverty, language barriers, immigration status, lack of insurance, and low levels of education represent a challenge to develop effective ways to communicate meaningful information to minority audiences considering best practices, family centered, and cultural competence/sensitive approaches. Following the work developed by the Wisconsin Family Support 360 project, which created a radio novella in both Spanish and English about important issues related to a minority family having a child with disabilities, this group will expand the idea, developing another radio novella that will focus on URLEND regional/local issues and priorities related to the disability field.

Optimizing feeding/nutrition support for young children with developmental delays

Feeding disorders are common in the preterm infant and young children with chronic and complex health conditions. Problems related to feeding come in many forms and are often interrelated. Inadequate nutrition results in increased stress and anxiety for parents and families of children with special health care needs. Resources are limited and difficult to access, leaving families without the support needed for optimal outcomes. The group will conduct a needs assessment and literature review that identify current services, resources and programs for addressing feeding concerns for preterm infants and children with chronic health care conditions. The information collected will be presented in a report or poster.

Building Cultural Responsivity: Reciprocal Learning Through the Development of Relationships With Agencies Serving Resettled Refugee Community Members

Trainees involved in this project include Deana Miller (Occupational Therapy, Boise) and Brian Peck (Social Work, Boise).

This project will explore and develop a relationship with the resettled refugee population in Boise. This is the first of a multi-year project that will provide a learning strategy not only for Boise, but also create a procedure so that other URLEND partner states could develop similar relationships in their areas. Trainees will develop a relationship with key stakeholders at a local medical center to become familiar with the needs of members of communities who have arrived in Boise via the refugee resettlement program. Trainees will become aware of and document the unique cultural and social differences and barriers to equitable health care faced by individuals with special health care needs in the population of resettled community members. Trainees will identify goals and objectives for a professional teaching/learning relationship between URLEND and the local medical center. Trainees will identify other key stakeholders who could be included in further outreach and collaboration efforts in the Boise area.

Up to 3 Parent Satisfaction Survey—Final

The trainee involved in this project is Brigid Crotty (Speech Language Pathology, Logan).

This is the culmination of a two-year project. During the first year, a survey was developed and piloted. Last year’s project was to pilot the survey and train Up to Three staff in how to use the technology so parents might be able to complete the survey on a portable electronic tablet. That pilot was begun, however difficulties in the reports that were generated proved to be a barrier to that project.
This one-semester project will be to work with the CIDI at Utah State University so that the reports generated by Qualtrics are usable to the staff and administrators of the Up to Three program. The trainee will develop a draft of a paper for publication, including the trainees from the last two years as co-authors so that this information can be shared with other service providers. Additionally, the information can be submitted to ASHA, AUCD and other relevant organizations for oral or poster presentation.