Academic-community partnerships in rural and frontier communities: Improving services for children with autism and other developmental disabilities in Alaska

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BACKGROUND

In Alaska and the US, access to health services for children and youth with autism and other developmental disabilities is seriously challenged by workforce shortages. These challenges are magnified in Alaska by the diverse populations and their wide dispersion. With funding from HRSA’s Maternal and Child Health Bureau for the Alaska LEND Without Walls (Leadership Education in Neurodevelopmental and related Disabilities), the University of Alaska Anchorage, Center for Human Development has pioneered partnerships with community organizations, family members, the Alaska Title V Agency, and multiple community and university stakeholders. The goal is to develop a uniquely Alaskan model with interdisciplinary, community-based, family-centered teams to coordinate leadership training and culturally competent service delivery.

ALASKA’S UNIQUE CHALLENGES

- Alaska is the largest state in the union, with 586,412 square miles
- One-third of Alaskans live in frontier/remote communities
- 75% of Alaskan towns are accessible only by air or boat
- Alaskans face additional health challenges due to environmental factors (e.g., extreme seasonality, cold temperatures, and poor air quality)
- 97 villages have 100 or fewer residents
- One in six Alaska residents are Alaska Native, the highest percentage of indigenous Americans of any state

HEALTH CARE SERVICES FOR FAMILIES AND THEIR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

- Approximately 12% of children and youth age 18 or younger in Alaska experience special health care needs
- 21% of Alaskan children lacked health care coverage in 2010-11
- Alaska Natives have the highest rate of reported disability of any racial/ethnic group
- Families in Alaska needing medical care are frequently flown into the nearest regional hub or Anchorage
- Multiple models of service delivery, based on tribal, private, and public healthcare systems, contribute to a complex system of health care and related services
- As a frontier state, Alaska faces significant shortages in health care workers

PROGRAM GOALS

Using distance delivered education technology and Alaska’s telehealth system, the Alaska LEND Without Walls aims to improve the health of infants, children, and adolescents who have, or are at risk for, developing autism and related developmental disabilities by preparing trainees from a wide variety of professional disciplines to assume leadership roles and to ensure high levels of interdisciplinary clinical competence.

1. Advance the knowledge and skills of professionals to improve healthcare delivery systems for children and youth with autism and other developmental disabilities in rural and frontier communities in Alaska;
2. Provide interdisciplinary leadership education to professionals, emphasizing integration of services supported by state, local, and private agencies and communities;
3. Provide Alaskan professionals working in rural and frontier communities with the skills needed to foster a community-based partnership of health resources and leadership;
4. Promote innovative practice models that enhance cultural competency, partnerships, and family-centered approaches to care; and
5. Provide interdisciplinary training opportunities to build capacity to screen, assess or diagnose, and provide evidence-based interventions to individuals with autism of other developmental disabilities.