

AUCD Rural Area Code Caucus (RACC) Discussion Agenda: In-person Meeting

November 17, 2019

11:30 AM to 12:30 PM (bring your own lunch/ food)

Meeting Room 16

Discussion Items

- I. Welcome and brief introductions. Marty Blair (MT)

- II. Transporting knowledge, services, expertise, etc. Tony Cahill (NM)
 - a. This discussion is grounded in the comments below. See page two for discussion framing questions.

George Gotto (MO): *"We have so many different ideas to transport bodies but I don't think we have made full use of technologies that help us transport minds and knowledge"*

Ethan Dahl (WY): *"While transportation is a great topic to approach, for many areas, physical transportation of bodies is just not a great possibility. Rural areas should be leading the charge on the transportation of expertise, learning, and resources via video conferencing and tele-models."*

Mark Smith (NE): *"Zoom helps, but our rural individuals and families at this point almost find it insulting."*

- III. What other issues should we address? What's the next discussion/ action topic? (Marty-All)
 - a. See January 2019 meeting notes on page three.

NO MEETING IN DECEMBER.

NEXT ONLINE MEETING: January 23, 2020, 4pm ET.

IV.

Discussion Framing Questions

Tony Cahill, Discussion Facilitator

- What models are UCEDDs/LENDs using in various services, including clinical and other direct services?
- What changes, if any, have needed to be made in the service delivery model from transporting people to “transporting expertise, learning and resources”? Have clinicians and others had to change the way they provide services using these models, and what (if any) has been the impact on their professional work? The same is true for capacity-building. For example, we have an ECHO-based Navajo health care provider professional development series, which conducts monthly cases analyses based on needs given to us from providers on the Nation.
- What barriers have been encountered, and what has been done to address them? For example, 70% of the Navajo Nation doesn’t have high-speed internet access.
- What has been the impact of these new models on the quality of life of people we serve? (...and wearing my hat as the evaluation director for my Center, who is attempting to measure that, and how?)
- What changes have been made in the infrastructure of UCEDDs to incorporate this new model; why were they made and have they worked?

It may be easier to define by saying what it isn’t:

- It isn’t just about ECHO, and in many ways it isn’t about technology *per se*. Incorporating technology into service delivery is about organizations and systems; those should be the focus. ECHO is a widely-used model (and it’s headquartered about a mile from my office), but there are so many other ways that videoconferencing and tele-models are being used successfully.
- It isn’t about using Zoom to hold meetings; lots of us do this all the time but that’s just an administrative “meeting extender”.
- It isn’t about someone in a suburb of Albuquerque connecting to us here at the Center; it’s about places, as Ethan said, where “it’s hours to resources”. Harding County here has a grand total of 740 people in 2,126 square miles).
- It isn’t about how these models are being used in the greater scheme of things; if we move forward this should be focus on UCEDDs working in rural and remote areas.

January 2019 Meeting Notes

To identify initial topics and priorities, several participants described the rural issues they are addressing well and those that represent chronic, perpetual challenges in their areas. The preliminary list is not exhaustive.

State/ Participant	Strengths	Challenges
Alice- Oregon (OHSU)	<ul style="list-style-type: none"> • Housing initiative with the DD Council. • Access to health care. 	<ul style="list-style-type: none"> • Transportation to services, etc.
Maureen- Maryland	<ul style="list-style-type: none"> • Awareness of disability services and issues through community organizations (e.g., Rotary). This has led to improved reach in rural schools. • Telemedicine increases reach but is not consistent statewide. 	<ul style="list-style-type: none"> • Transportation • Access to health care services.
Susan-Texas	<ul style="list-style-type: none"> • Genetics training for some families, but many communities does have genetics providers. 	<ul style="list-style-type: none"> • Poor internet access; adequate broadband access and speed.
Tafa- American Samoa	<ul style="list-style-type: none"> • Bandwidth is now steady for Telehealth and Telemedicine services. 	<ul style="list-style-type: none"> • Human security (e.g., emergency prep, disaster prep, political unrest that impacts distant territories but not continental U.S.) • No PKU/ genetic testing. • Nutrition (e.g., iodine) and food safety.
Greg- SD	<ul style="list-style-type: none"> • Connecting with like-minded community groups (e.g., Rotary, Chambers of Commerce, AARP) and community “bridge-building.” 	<ul style="list-style-type: none"> • Transportation • Statewide reach beyond urban centers (beyond I-90 corridor)
Lori- ND	<ul style="list-style-type: none"> • Communication across agencies. • Relationships with like-minded partners 	<ul style="list-style-type: none"> • Lack of services in behavioral health. • Affordable accessible housing.

State/ Participant	Strengths	Challenges
		<ul style="list-style-type: none"> • Transportation (#1 priority). • Access to health care and insurance. • Employment and competitive wages (e.g., 14c issue).
Marty- MT	<ul style="list-style-type: none"> • CIL relationship and health promotion. • Collaboration with pediatric healthcare system. 	<ul style="list-style-type: none"> • Access to appropriate healthcare. • DD services workforce development and staff retention.