



Membership Discussion

Facilitator: Maureen van Stone

Summary of breakout sessions:

- Social determinants of health/ACES
 - CA: administering ACES screening, potential in evaluating early screen
 - While it's important to do screening in pediatric clinics and incorporate into curriculum-
 - If children screen positive, what next?
- Rural areas/territories
 - Project ECHO models
 - Summary from Marty Blair: ECHO was only an example of the larger issues related to telehealth. We discussed the possibility of bringing the varied telehealth interests together into network community of practice so that we can learn from each other. Some UCEDDs are statewide telehealth/telemedicine coordinators (WY) and others are just dabbling. There is wide experience and lots to learn from each other. There was also a discuss re: the need to address housing issues (accessible and affordable). The stock is limited in rural areas and is often "snarfed up" when new business comes to town (e.g., oil booms, new factory opening, etc.)
- Person-centered thinking and supports
 - Masters-level program for supported decision making
 - "Parent academies:" so they have adequate information for transition from high school
 - Need to be on the same page so that we work from the **same definition**
 - How do we change expectations? How do take these topics out of these buckets so that they are not viewed as separate when they overlap quite a bit?
 - The term "person-centered thinking" might not apply across cultures
 - Peer to peer person-centered planning (train people with lived experience)
 - How do we convince agencies to do things differently?
 - How do we partner together to spread the message more broadly?
- Inclusive partnerships (self-advocates and researchers)
 - Review of existing resources
 - Attitudinal barriers, workforce development needs
 - Need for additional tools for researchers on participatory models
- Working with partners (DD and state advocacy)
 - Challenges; some are more effective than others
 - Assignment for AUCD: develop a resource that highlights the benefits of network engagements, plus examples of good practice and effective engagement



- Joint needs assessment
- Need to remain neutral, especially with PNAs
- Workforce
 - Need to collect data around workforce issues across the network
 - Variety of training programs to learn from
 - Occupational categories- inconsistent (federal and state level)
 - Medicaid limits to direct service professional pay
 - Reinstating Projects of National Significance
 - Come up with national-level activities, modules (birth to geriatrics)
 - What skills/knowledge/training do professionals need to do their job?

Areas of Impact? Opportunities for Collaboration?

- Network has had significant impact on the lives of people with developmental disabilities in the last few decades
- No unfunded mandates
- Can we amplify each other's work?
- Need to capture areas of impact, examples. Capture how much the landscape has changed- what is our place in it?
 - "Community of Learners"
 - Demonstrate and model good collaboration
 - Share definitions
 - Impactful contributions
- Highlight our contributions AND the various partnerships we have forged and grown (or lost) in order to make positive change.
- Need advocates, beneficiaries to evaluate our contributions and share the message, otherwise it's very self-serving. Voice of people with disabilities and families is a must.
- Journal? Book? Needs to have visuals.
 - Utah: Developmental Disabilities Network Journal:
<https://digitalcommons.usu.edu/ddnj/aimsandscope.html>
 - Editorial board is made up of UCEDD directors
 - Open-source journal, collaborative effort
- Interactive map
 - Plain language one pager that highlights network efforts
 - Inclusive, vignettes and story additions
 - (originally a product for the Gala- focused on state policy)
 - Map- What is each UCEDD known for?



- Podcast that rotates across the network. I know some UCEDDs have Podcasts, but not all have enough content or bandwidth. But if we all volunteered for a few podcasts, that would fill a lot of content.
- The inclusion small group talked about the possibility of a fact sheet or toolkit that describes for researchers how to engage community members, including people with disabilities, in the entire research process, from initial question through analysis, etc. This would make a positive impact, rather than, or in addition to, a retrospective or congratulatory celebration.
 - Maybe a Factsheet on this that can be shared with partners outside of the disability community (how we can help/support them)
- Explanation of the DD Act would be useful
 - Video, professionally edited and produced
- If we are contemplating activities or products around the DD Act network we need to include the other partners in the planning & decision-making
- As far as the 50th anniversary is concerned, we need not only to look back but also look forward. What should reauthorization of the DD Act look like? What will the next 50 years bring to our field and most importantly the lives of people with intellectual and developmental disabilities and their families?
 - Include the impact on children, adults, and families in the video.