



## Discussion Notes

**Topic:** Working with Various Partners

**Notetaker:** Natalie Martinez

**Participants:** Rhonda E, Cindy Thomas, Brian Freedman, Deana Buck, Evan Dean, Kathleen Sheppard, Amy Sharp, Chris Knowles

### Discussion Questions:

1. Where can the UCEDD network work together? Cindy- Looking at needs assessment that needs to happen every 5 doing it collectively together. Doing an update rather than a full blown assessment. What are their common agendas? Rhonda- curious any convos on how that needs assessment might rollout- question to Cindy. Cindy- very early convo stage. Might find diverging different perspectives. 2 UCEDDs in MA- they have different focus areas and make sure they get the kind of input they need for all of their needs. Brian- thinks it is a great idea. Likes the idea of a shared task and then supplements then for what each network partner needs. It would a nice way to blend the communities, nice convos about shared goals. Cindy- wants the capacity to do more community forums, development of videos, etc. accessible for people to help them understand what the UCEDD is trying to do. More united, comprehensive front on the 5 year report. Deana- let their legislative communities know what is important to their UCEDD. Kathy- plain language formatting the results you are sharing using plain language make sure we are reaching the broadest audience.
2. How would the collaboration look? What are the actionable steps that need to happen to make those collaborations happen? Rhonda- that one of the places where we find challenges. Each of the DD network partners are busy with their stuff, leadership transitions. Trying to get together as a network. Need advice on how to develop a strong network together. Cindy- add value to the P&A and not challenge legal. They know the provider community like the P&A doesn't. Evan- good working P&A and DD council, the last couple years have grown closer, identified a few issues where they are all in sync- particularly around the final settings rule and supported decision making.



3. What would be the outcome of the collaborations? (Products? Tools?) Evan- some way of providing exemplars of working with DD networks across the state. Working with state on NCI and system level reporting- interested in hearing about other states that are doing that and what their experiences are. Rhonda- I learn when we have an opp to talk about what we are doing. Do a network approach and connect on topics that each other are working on. Figure out ways we can connect and instead of meeting once a year. Cindy- would like to see examples networks who have worked together. Kathy- a brief that comes out of AUCD- if she has something that she can go to on the website and she can pull off to see what different states are using- broader topics. Brian- it would helpful to share with our partners. Cindy- it would align with what they have heard from the feds about working together.
4. How would those products be useful? Cindy- would like AUCD to pull examples form across the network and how they are working effectively from across the states.
5. How can network members can support one another in addressing barriers/moving the needle? Amy- the doc that was suggested would be helpful to help start ideas. Deana- are there other resources for directors to get together or collaborate besides the listserv?
6. Where do we go next as a Network?



## TA Institute Discussion Notes

**Topic:** Person Centered Supports

**Notetaker:** Denise Rozell

**Facilitator:** Angela Martin

**Participants:** Pat Morrissey, Angela Martin, Olivia Raynor, Lori Garnes, Colleen McLaughlin, Lesley Cottrell, Fred Biasini

### Discussion Questions:

#### 1. Where can the UCEDD network work together?

Real life is not reflecting person centered planning/practices

**Network statement** about the vision, examples, what do we envision it looks like, be implemented- collective statement and tool

Look at different topics...**how they align**; DSP, systems issues; community inclusion; all fit into each one; come together in alignment in topics – HCBS Settings Rule!!

Beyond jobs led to looking at careers; similar here – **expect** people with disabilities to be included in all levels of decision making (how to help states get to that place? **Too many buckets and silos**)

How do we help states get beyond silos and buckets...

What is a person centered plan? Definition agreed to; teach it so others can be leaders to others; Minot has a Master's degree in Human Services...ID/IDD...; elevate the workforce so they can also teach it – get it out of the universities to the workforce [MI: or using people with lived experience training to lead in person centered planning to avoid conflict of interest]

Training in the homes of what it means to do person centered planning

Cultural and linguistic competency for person centered planning! Words we use can be offensive or not translatable/transferable. Culturally respectable for all communities – e.g. "family centered"

Charting the Lifeforce

#### 2. How would the collaboration look? What are the actionable steps that need to happen to make those collaborations happen?

Still issues of what does HCBS means? RFPs coming out?? –



10 UCEDDs doing the same thing 10 times to have collective impact and then share information/resources - partnering

**3. What would be the outcome of the collaborations? (Products? Tools?)**

Legislation?? Give money to someone to do something differently... (example Hawaii Transition Success Network – through Senate, next week House)

Legislative proposals that we share with folks in an election year... (could influence elections)



## TA Institute Discussion Notes

**Topic:** Social determinants of health, ACES, working across different systems

**Notetaker:** Maureen Johnson

**Facilitator:**

**Participants:** Sharon Milberger, Danny Armstrong, Kara Ayers, Suzannah Iadarola, Karen Bonuck, Larry Yin, Maureen van Stone

### Discussion Questions:

#### 1. Where can the UCEDD network work together?

SM – Add this to an existing SIG and identify who across the network is an expert on this topic

KA – Medical education, coordinated and collaborative method

SM – Share grant and training opportunities

SI – Share across disciplines

LY – CA State is now providing extra monetary incentives to pediatric centers in support of additional ACES (Adverse Childhood Experiences) screenings, network can support and advocate for policies across the network that promote increased screenings

SM – Get information on who in the network is doing trainings

LY – If more positive screenings are determined, what are the resources available?

#### 2. How would the collaboration look? What are the actionable steps that need to happen to make those collaborations happen?

LY – Keep an eye on screening rates and the experiences of people who have implemented screenings in pediatric centers

SI – What are the outcomes that are measured?

LY – Need to look at research to determine outcomes to measure



DA – Look at the relationship between positive screens and health outcomes and tie it to value care and reimbursement, social determinants play a big role, network could focus on a few specific determinants and show if they are strong factors and if modified will they change the outcomes

LY – Could start to look at certain populations like people with medical complexities

### **3. What would be the outcome of the collaborations? (Products? Tools?)**

SM – Good to have a depository of tools and resources used throughout the network

LY – UCEDDs could collaborate in research

SI – create an implementation toolkit using CA as a model

SM- potential research opportunities

SI – use data from multiple states to encourage and direct research ideas

DA – validate tools

### **4. How would those products be useful?**

DA – can show links between social determinants and the benefits to the patient in terms of outcomes, ex: a child with asthma with X medication and a model adjusted with social determinants like home environments, shows how social determinants works with supports already in place, how can selected services be delivered to produce a better outcome, results-driven method

SI – can enhance family-centered care, discussion with families build trust and engagement, can promote relationship building

SM – can enhance interdisciplinary professional practice

SI – to what extent have the guidelines of the CA model (PEARLS) been cultural informed?

LY – tool (PEARLS) hasn't yet been validated, let's validate it to show that using this tool can make a difference

### **5. How can network members can support one another in addressing barriers/moving the needle?**

SM – sharing successes and opportunities to collaborate, also lessons learned



LY – share challenges

**6. Where do we go next as a Network?**

DA – hard to consider when this a national issue, maybe a panel discussion at the conference for members to share strategies, individual institutions could take the lead and form collaborations, need groups of people interested to come together and determine how to fund collaborative efforts

LY – Opportunity for AUCD to keep tabs on this topic as we move forward

LY – CA screening tool referred throughout conversation: **Pediatric ACEs and Related Life-events Screener (PEARLS) Screening Tool**– developed by the Bay Area Research Consortium on Toxic Stress and Health (BARC), a partnership between the Center for Youth Wellness, UCSF Benioff Children’s Oakland, and the Adversity Bio-Core (ABC) Bank at the UCSF School of Medicine and Pharmacy



## TA Institute Discussion Notes

**Topic:** Promoting Inclusive Partnership

**Notetaker:** Sarah DeMaio

**Participants:** Cari Murphy, Liz Perkins, Carol Curtin, Derrick Willis, George Gotto, Ilka Riddle, Karen Ward, Mark Crenshaw, Susan Hetherington, Tawara Goode, Melanie Fried-Oken

Suggestions on how individuals participate in research. Creating meaningful partnerships that aren't just sign on letters of support.

CBPR – Carol Curtin – How can people be successfully included? Qualitative study, Self-advocate reviewed interview guide and recruitment materials?

What can we do that has few barriers?

- Interest in developing a fact sheet helpful for all stakeholder, what does it mean to have true inclusion of people with IDD in research.
- Tawara has a PCORI project and is developing some of these tools, too many tools are for families and self-advocates and tools need to be developed for researchers. People who are new immigrants and people from historically underrepresented communities have a legacy of mistrust that needs to be addressed.

How do we take a step back to find out what are the topics for research based on lived experiences of community partners? "How do we do research that is meaningful for people from these communities" is a different question from "how do we engage these communities in the research that we want to do."





How do you create the research from the beginning that involves people?

- There were no people from the community involved in developing the question and establishing the design. Challenges – timelines, types of research that you're supposed to be doing, not having flexibility, what money you are supposed to be bringing in.
- Changing the culture of how people think.
- Some people don't want to do things differently, some institutions don't value this type of research.
- NIH says that you are supposed to be more inclusive
- Attitude and knowledge barriers. Need leadership to talk about research in different ways.
- Tawara is developing tools (including briefs and videos) about involving people with language and communication access needs in research.

Workforce issue.

- need a pipeline to engage in recruitment, training, engagement in those communities.
- Some tools are out there – the Action Plan from yesterday, the Diversity & Inclusion toolkit
- How to promote and leverage those? Fact sheet would be helpful.
- CAC resources and mentorship – if asked for support, here are things you should consider
- Susan Hetherington – Having Factsheet/toolkit for researchers, there is an appetite – she hears people talking about it but people don't know how to do that. Providing support so people have something to go on since it's not an easy thing.
- Youth Participatory Action Research curriculum has been tweaked. It's time consuming. You have to spend time on education along the way. working with 4 H and school seminar groups. One semester doing education, help kids to develop a question and carry out a project, then help them translate the outcomes into something useful to the community. Research indicates that without the ACTION piece then you don't get the good outcomes. George can share.
- Oregon has also used this curriculum.

Ilka – people appreciate inclusion of a lot of different groups but when it comes to PWD that seems to be received differently. How to get people started getting to be more open? Awareness raising.

Tawara - Biases on part of researchers. Need the carrot and stick approach.

NIH funds is promoting the inclusion.



People have concerns about consent. Diversifying research pool and look at ways that people can be included.

Video narratives from a variety of perspectives

Tools, plain language informed consent tool that was developed informed by a group of people with IDD.

Critical need for people with IDD and MH – they are over medicated, treatment is not based on the science.

Oregon – panel discussions at the pre-service levels in MD, PA, RN schools and now adding PhD programs. Panel has people with IDD who use communication devices, a parent, a professional from discipline, has been really well received.

Network white paper - questions to ask in PhD programs related to research and questions by all different stakeholders.

Mark – Network could support each other about models for conversation when it goes well. Tools related to this issue sharing the value of participation from perspective of self-advocates.



## Discussion Notes

**Topic:** Workforce- service providers, capacity, wages

**Notetaker:** Luis Valdez

**Participants:** Wendy Parent-Johnson, Dana Yarbrough, Mary Beth Bruder, Amy Hewitt, Mark Shriver, Karen Heath

### Background:

What are some of the issues with workforce?

- **Wendy Parent-Johnson:** having the skills; state systems don't recognize this as a career path. Looking at a blanket statement of what is needed across all avenues.
- **Karen Heath:** Medicaid limits – wages can't increase (limits in apprenticeship programs).
- **Amy Hewitt:** Often go through the trouble of building the infrastructure, but we need to get the right message across at both the federal and state level (legislative bodies). "Increasing wage" can't be the only message, need to use the data to inform the message. Occupational title is often a problem, as people in the workforce can go by many different names, need to differentiate and define the differences.
- **Mary Beth Bruder:** We have an early childhood TA center to help states look at sustainability, but turnover is so rapid. The whole field needs to be looked at as a career option.

### Discussion Questions:

#### 1. Where can the UCEDD network work together?

1. **Dana Yarbrough:** Doing something together with the data.
2. **Amy Hewitt:** Map out ways if you want to go into community service pathways (using data).
  1. Also, workforce issues often get filtered through to politicians from other organization and never directly from the workforce themselves. Direct service professionals need to tailor their message in ways that convey the skills they have rather than focusing on the caregiving aspect. These stories must be told to the policy makers directly from people themselves.
3. **Wendy Parent-Johnson:** Professional development – preservice or in-service side to respond to requests from agencies.
  1. **Mary Beth Bruder:** Everyone needs training. Can look into online modules that can be shared across states and the development of standards.
  2. What kind of professional development opportunities can we provide that anyone can access? We can tie these into national standards across the network.



3. **Amy Hewitt:** Serious need for intervention-trained people in positive behavioral supports and other interventions, especially for early intervention and ongoing in ASD.
  4. **Amy Hewitt:** only have a few BCBA certified people at center and need more.
  5. **Mark Shriver:** Need for training in state; need for personal preparedness training on all levels.
  6. **Dana Yarbrough:** Hiring people with disabilities to do trainings. Actively looking for grants to build a corps of people for this function.
2. **How would the collaboration look? What are the actionable steps that need to happen to make those collaborations happen?**
1. Collect data right now around what the network is doing in this area.
  2. **Karen Heath:** Develop core competencies for direct service professionals (Alaska willing to collect)
  3. **Wendy Parent-Johnson:** Can we continue this conversation with a dedicated group?
    1. **There was significant interest in continuing this conversation in the form of a workgroup dedicated to this topic.**



## TA Institute Discussion Notes

**Topic:** Rural areas and territories (infrastructure, transportation, cultural considerations)

**Notetaker:** Dorothy Garcia

**Facilitator:**

**Participants:** Michelle Aguigui, Leann DaWalt, Sandra Friedman, Marty Blair, Sandy Root-Elledge

### Background

- Kimberly Mills: Recent conversation with Brent Askvig- infrastructure challenges
  - Transportation will always be an issue for ND (similar for VI UCEDD)
  - Paratransit system in VI doesn't operate past 5:30 pm
- Sandra Friedman: trying to support primary care providers in rural areas by giving training, TA in how the assess and manage patients, sharing resources, building capacity so that there's no need to refer as much to Denver (funding through Medicaid)
- Sandy Root-Elledge: We coordinate telehealth for the state, building capacity for patients and providers to connect remotely. There are increases every quarter. (partnership through Wyoming Medicaid)
  - Model to share with other UCEDDs?
- Leann DaWalt: Sent a team to Wyoming to be trained in the ECHO model
- Transportation, Infrastructure (ECHO could be a solution to transportation)
- Housing
  - Too large an issue for the territories; not enough housing; VI is still in recovery
  - UCEDD in preliminary discussions with an architect about a certification for universal design to address the issue of inadequate accessible housing

### Discussion Questions:

#### 1. Where can the UCEDD network work together?

- ECHO model, telehealth communities of practice
- VI just landed a sizable telehealth grant. But any practitioners will have to be dually licensed for both mainland US state and a territory
- Private companies do telehealth, physicians can sign up to provide service through telehealth (but need to be licensed in other states, which throws up another obstacle)



**2. How would the collaboration look? What are the actionable steps that need to happen to make those collaborations happen?**

- How do we learn from each other (learning collaborative)? How do you engage people? What's the optimal number of groups?

**3. What would be the outcome of the collaborations? (Products? Tools?)**

Telehealth Community of Practice

**4. How would those products be useful?**

- Tricks of the trade to be learned, people who are using these platforms
  - Example: Virtual TA Institute
  - How can you strengthen the experience?
- Addresses infrastructure and transportation challenges
- COVID-19 makes it more urgent to learn how to provide services remotely
- We need to help people who are geographically dispersed?

**5. How can network members can support one another in addressing barriers/moving the needle?**

- Entire network can benefit, has applications across the network, and not just rural areas or territories

**6. Where do we go next as a Network?**

- Should we develop a SIG? (currently looking to reduce number of SIGs, but this is a pressing issue for everyone)
- Rural caucus- provides a much-needed perspective that is often excluded in policy discussions
  - 2-year community of practice?
  - Would be great not to add to the number of existing groups