

# 2017 UCEDD TA Institute

## Plenary Discussion – Notes

### Plenary: Update from AIDD (Thursday 8:45-9:30 am)

- Current staff in place are in acting roles while the administration interviews political appointee replacements. If past is prologue, political appointments may be late spring/summer. Dan Berger meets weekly with ACL team and Policy team assigned to ACL; teams consider decisions regarding funding and policy. Currently all is working as usual.
- Funding- what Congress might decide to provide in terms of appropriations for FY2017
- Administration's budget will focus on spending with regards to defense and homeland security, which shows a preview of its priorities, but Administration has yet to provide updates. No indication yet of priorities with regards to HHS programs. 18% reduction of annual levels.
- Mental health & substance abuse crisis is a priority
- Major investment with PNS funds to bolster business acumen (funded through PNS)
  - ACL has been investing in this area to support community organizations
  - Organizations that have participated in these programs have been able to diversify their funding sources.
- Secretary Price: People, Patience & Partnerships
  - Measuring the effectiveness of the programs you're funding
  - What stories can we tell using trend data?
- Despite uncertainties, they are moving along so that they'll be in a position to make awards and finalize budgets once appropriations have been decided
- OIG report: Incident reporting process is not going well: state plans are well-written, good procedures, but there's no oversight

### Plenary: Emerging Employment Agenda for Youth with Disabilities (Thursday 9:30-10:15 am)

**Madeleine Will: We cannot sacrifice another generation of young people with disabilities to poverty.**

Progress Made –

- Looking back, the Reagan administration's plan to block grant IDEA resulted to 100K letter outcry. The subsequent rebuilding relationships resulted in the waivers.
- The current re-alignments happening in an environment of political gridlock, speaks to the power of the disability community. Consider also, some significant changes that result from employment expectations post education.
- Difference in goals from the 1975 IDEA, which focused on addressing educational discrimination, to the most recent reauthorization of the IDEA, which calls on ensuring access to general education curriculum to prepare student for employment/higher education. This would have been preposterous in the 1980s, but has been reaffirmed by the recent Supreme Court decision.

**Move to Employment First** - establishing employment as the preferred outcome (33 states have initiative, directive or legislation). 44 states have some Employment First activity.

**Higher Ed Opportunity Act** has special section on including students with disabilities in higher education programs reflecting the blossoming of PSE programs which expanded in number from 35 to 260 programs with focuses on skill development and employment. This has drawn increasing attention to the needs of adult students with disabilities, with a Congressional Accreditation task force to evaluate these programs. This taskforce is currently in their second 5-year period of developing standards.

**WIOA authorization** - definition of competitive employment and customized employment, again with a focus on skill development/employment. Includes piece on state programs to document on how agencies will collaborate and how to resolve

issues around funding Blending/braiding, new focus on this individual level of focus. States had before be doing this sequentially rather than an integrated approach. HELP committee lead the way of this change. Focus first on EF states.

The ABLE Act of 2014, which took 10 years to get passed, creates tax exempt savings mechanism for individuals. 30 states are now working on state legislation for implementation. This program will grow in importance as a way to allow individuals to create asset base.

### **Progress yet to be made - Ideas being discussed for modernization and reform**

- Change the age of determination for SSI from 18 to 22 to avoid the disruption and align transition process, Side note: SSA currently protects individuals from denial if they receive employment supports at age18 (people are not aware of this)
- National paid internship program - looking at IDEA reauthorization to incorporate WIOA Employer payroll tax roll adjustment for those employing an intern, however, benefit offset needs to be a consideration.
- Amend SSA to exclude benefits accrued under employer retirement contributions

CPSD has produced a package of legislative updates. The full package is difficult to pass because congress is so siloed, but pieces have been included in recent legislation. The next piece to focus on is OMB involvement in interagency activities to better align interagency activities (budgets, staffing, evaluation, outcome measures, provide recommendations on additional research). Also benefit offsets and SSI overpayments. We had language to study this issue because it's not acceptable to penalize the beneficiaries for SSA's mistakes.

### **Q. - federal policy works at a glacial pace, but other disruptions are happening in the workforce that are having rapid effect - what can we do to address these needs?**

We need to partner with local business leaders. We aren't talking about a huge number of people to focus on. If we could focus attention on addressing those needs and involve families at an earlier age to remove fear of loss of benefits, we could start to see progress. We need benefits counselors, teachers etc. to be aware and address the culture of fear in parents. We also need to increase internships, particularly paid internships.

### **Q. - Given your lens, how can we take the message that PWD can be a valuable employment resource to this admin?**

RE this admin, I have no special insights other than that it matters to officials that PWD are not pleased with them. We need to be open to reconciliation. Otherwise they might write the community off; we don't want them to just stay away or to feel that it's better to "just leave well enough alone."

### **Plenary: HCBS Settings Panel (Friday 8:45-9:30 am)**

- Implementation of the Settings Rule- Deadline for states and compliances is March 2019
- How do you evaluate settings? How do you validate self-assessments?
- Letters are public record on Medicaid.gov website (approval letters from CMS, responses)
- On a state advocacy level, good idea to make public any success stories
- States often lack expertise to implement proper assessments, lack of personnel training
- How will the state plan to keep settings compliant?
- In terms of remediation, what are they looking for?

- Refer to Secretary Price and Director Seema Verma letters
- The areas that are critical are the questions of assessment and monitoring and states lack expertise and resources to do this right.
  - Having a good tool is very helpful
  - States are now working on validating provider self-assessments.
  - Who's doing these? Do they have conflicts of interest? Are they being uniformly trained.
  - Attachments to CMS- states have to come up with a plan to build capacity as they go forward and that's a great place to interject ideas (e.g., tiered standard approach)
- Use data to drive decision-making, move away from anecdotal stories
- Heavy lift: ongoing continuation of quality management of services
- Reliance on licensing and regulatory systems
- Formulas will be driven by growth patterns, states need to know their trends
- Medicaid discussions
- Important for states- if indeed, the per capita counts continue to arise, those formulas will be driven by data (who is coming into services, what is the cost of those services)
- For supporting kids- are they coming in at child welfare or other places?
- Those formulas are used to determine how the money is coming into the state, not how it is distributed
- Need to be able to understand trends as future discussions are had

#### Pennsylvania

- Plan was submitted in March 2016, initial approval in August
- Provider community response was intense- over 2000 comments were received during public comment
- Plan hinges on successful renewal of waivers
- Initial submission of waivers was very submission, sheltered workshops
- Size was important, as well as the time spent outside the program
- Facility could not be larger than 100, new facilities not bigger than 15
- UCEDD heavily involved with office of developmental programs; have a strong DD leader with a great background
- PA collects 5000 face to face surveys, collected by 2 person teams, one of whom must be disabled, or a family member of a disabled person
- PA is unique because of the number of surveys; they have access to setting-level data, incident management, etc. to inform families

#### Have you identified Republican governors with support for the Settings Rule?

- Ohio, Governor Kasic
- Tennessee is the only state with final approval

Depends on what kind of heavy lift and transformation they have left to do. Some states have been getting funding to deal with it, more on the operational level between the state and Medicaid

- Unevenness in specific areas- identifying settings that isolate, identifying good practice. Much more rare to find a state that has put it all together
- Self-advocates are involved in the teams collecting the information
- One of the reasons initial plans were rejected was because of lack of involvement from self-advocates

#### Conversations with NASUADD:

- Aging and Disability Waiver seems daunting for NH
- Assisted living facilities are pretty normative, how does that compare with someone who has a DD at 25?
- CMS has heard those areas, can you identify without making it population-specific?
- Can you have a community-based service that is in a group setting?
  - Might be flexibility in the guidelines from the Secretary?
- Tracking director turnover shows high turnover (15 out of 51 leave in a year)

How is managed care going to affect implementation of the rule?

- Look towards the private center, still major goal for the state office
- What are quality outcomes, what are the expectations for providers?
- Look to Tennessee for an example of how to engage
- Lay out clear responsibilities- state role vs Managed care responsibilities

### **Takeaways from breakout groups:**

#### Education

- Identify ESSA state plans, opportunities for UCEDDs to be involved in crafting state plans
- Help inform families and diverse communities to understand the consequences
- More and more decisions will come down to the state level

#### Employment

- 27 states participated
- Innovations on a national basis
- What is it that states are going to do anyhow, no matter what happens at the federal level
- Interest in keeping AUCD conversation going

#### HCBS Quality

- How do we document/measure quality?
  - AUCD needs to facilitate/moderate
  - New portrait of UCEDD impact
  - AUCD should go independently to OMB
  - Workgroup on possible network-wide indicators (satisfaction measure, knowledge question, need more)
    - What are the questions we want to answer to tell our story?
    - Leveraging outcomes
    - Explore possibility of AUCD as monitoring vendor
  - Quick and dirty survey on what collaborations are going on between UCEDDs, formal informal, funded, unfunded, purpose, topical
  - Proposal for a panel for the fall conference (HCBS)
  - Network state agency collaboration- addressing best practices

#### Medicaid

- Not always clear who to engage with and how
- Capacity building: operations and deliverables (because of every state has a different Medicaid program)
- Opportunity around measurement and impact
- Collaboration and next steps
  - As a standalone, single-entity UCEDD, difficult to engage
  - Medicaid, banking and insurance, provider agencies, peer review, AUCD, platform or venue at the national level
  - Broadening engagement at the national level
- Help all constituents to understand risk management and value contracting
- PACE programs – Innovation Act of 2015
- Toolkit: for a UCEDD to navigate identify opportunities for change and the means to accomplish that change, evaluation, negotiation, models of delivery- deeper understanding about how to use its resources to achieve goals

### **COMMON TRENDS**

- Disseminating information in a timely way
- Ways for AUCD central office to build partnerships on a national level to facilitate relationships at the state level
- Opportunities to engage with universities as employers
- How do we integrate with the SILs
- Look at what would specifically link across programs, threads across ACL programs