

2017 UCEDD TA Institute

Tiered Breakout Discussion – Notes

Topic (check one): Employment HCBS Quality Medicaid Education

Facilitator: Rachel Patterson

Tier A: General Content (Thursday 11:00-11:45 am)

Facilitator began an opening topic on understanding what relationships people in the room have with Medicaid and what they'd like to get out of this breakout discussion.

Discussion around each state and/or UCEDD relationship with Medicaid and Managed Care Organizations (MCOs) with key topics:

- Each relationship with Medicaid and MCOs is different depending on the state and UCEDD; the structure and collaboration vary by state.
- Some states are early in their transition to MCOs whereas some states have already transitioned.
 - For states already transitioned, there have been issues with MCOs promising a lot in the beginning and then unable to deliver. For example, an issue with MCOs is that they don't want to pay rates to support people with complex conditions in community settings. Providers are struggling with late payments and restrictive pre-approvals.
- The relationship between MCOs and Developmental Disabilities providers also varies by state.
 - Some UCEDDs are actively working with Developmental providers to assist them with learning the MCO system.
- Technology is a big incentive when recruiting, retaining and supporting providers in Medicaid and MCOs.
 - Technology is one strategy to make the argument to the payer of what is the most cost effective way to achieve a standard of care.
- One UCEDD is interested in working on innovative ways to work with MCOs to develop new systems of care that have the kind of impact that we desire for the patient and families across acute/tertiary/developmental care.
 - Medicaid, under current model leaves institutions about 20% below cost (hospitals and providers).
- Concern was expressed regarding what will have to happen at the state level for sustainability if Medicaid gets block granted
- One state, Tennessee, has over two decades of managed care;
 - Generating a quarter to half a million dollars in clinical revenue which is decreasing; looking to learn about UCEDDs with creative relationships with MCOs and help them see the value added approach.
- Several UCEDD staff voiced that they were looking for ways to help their state avoid mistakes that have happened in other places.

Facilitator moved the discussion to opportunities for engagement in your states (PowerPoint presentation in pre-meeting reading materials touches on this)

- Your state needs to have a Long-Term Services and Supports (LTSS) advisory group that gathers input about what's happening in the community and report on data – how is the group getting formed, who is on it, how can we be involved, etc.
- Member advisory committee for each MCO that needs to include a “reasonably representative sample” of the LTSS population (CMS hasn't clarified what that means).
- Beneficiary support system to help people access and learn about / navigate the system – have oversight and reporting job; can do this in collaboration with Protection and Advocacy (P&A) groups and UCEDDs can be the oversight/reporting arm – make data publicly available.
- Required to include quality measures and have a state quality strategies; needs to contract with an external quality review organization and choose activities for their respective contracts.
- In acute managed care, there's a thing called network adequacy (exists for LTSS, too); time and distance standard for when the beneficiaries travel and another standard for when they don't – states are developing these right now; good opportunities for UCEDDs to add input (e.g. make sure the services are robust and not just, for example, in one part of the state or only sheltered workshops).

Discussion points from UCEDD Directors

- Waivers [in Pennsylvania] are being renewed right now and there's an outcry around the attempt to reduce the number of people in sheltered settings... could these successful lobbying groups say that there needs to be sheltered work options and backfire against us?
- Many primary care physicians PCPs not participating in Medicaid Managed Care (only 70% nationwide according to 2011 Decker survey).
- Creating networks without adequate reimbursement is problematic.
- There's a lack of understanding in MCOs around modern disability policy in practice (e.g. sheltered workshop vs. employment first) – they don't know what they're supposed to be creating.
- Reimbursement rates are low and payments are delayed means that small providers are having to take out loans to make payroll.
- For-profit Medicaid plans are doing well because they can move money across state boundaries without any state oversight – they can't look at national service vendors (“delay, deny, down code”).
- MCOs arguing that the state did a bad job of estimating the cost of providing services in the system.
- The Arizona State Developmental Disability agency is considered an MCO for providing care to the DD community and other MCOs provide services to other populations.
 - Several bidders contacted us [Arizona UCEDD] for input and want to include us in their plan to provide training to their staff, and they want us because they have to show innovation.
- One MCO [in Ohio] said that they knew how to do things like care coordination regardless of a child's condition, but there are real differences between kids with DD and kids with other medical conditions; it's not going well now that our kids are enrolled.
- Florida created a set of contingencies on the back end if MCOs didn't deliver on quality indices, so it was possible for companies to lose their allocation; state was so invested in converting to managed care that they have not enforced the penalties in the last five years.
 - Medicaid funding is inadequate to support the service models needed.

Tier B: Relationship Building (Thursday 1:15-2:00 pm)

Facilitator began the discussion on engaging with advocacy coalitions outside of the disability community.

Discussion around each UCEDD's engagement with advocacy coalitions:

- Several UCEDD directors work with coalitions that are focusing on the theme, "save Medicaid.
- Some UCEDD directors are unsure of to what extent the Developmental Disability coalitions are engaging with others.
 - In Oregon, there is the "Oregon DD Coalition" that's trying to reach out to non-DD groups (employment, aging, etc.) – working toward a select-invite statewide conference in May 2018 with the focus on how to create synergy / combine efforts.
- In Arkansas, the local AARP chapter is restricted in what they can do that's not part of their national agenda.
- Engaging partners outside of the disability community by focusing on community living and technology.
- Conflict with other advocacy groups arise when they only focus on aging-related disabilities.
- Several UCEDDs work successful with children's group through Title V, pediatric medicine, foster care and nursing programs.

The group asked about the American Health Care Act and what's at stake re: Medicaid

Facilitator explained that when it comes to saving Medicaid from caps and bad policies that don't actually hold the "most vulnerable" people harmless and to work with university/hospital administration networks for an advantage. Also, focus on the governors as they're the ones who are going to struggle when/if the federal government passes the Act.

Tier C: Capacity Building (Thursday 2:15-3:00 pm)

Facilitator shared that major concerns about work requirements for Medicaid access, from Secretary Price's letter, and could be an opportunity for people who work on employment. Facilitator moved onto a discussion on capacity building and Medicaid.

Discussion around capacity building in each state and/or UCEDD with key topics:

- One UCEDD voiced hesitation at partnering with MCOs due to the MCOs poor performance and did not want the partnership to be viewed as an endorsement.
- Arkansas used the navigator grants, before state legislature mandated a stop, were a great way to have an influence.
 - Acting as the navigator was good for an organization that knows disabilities and to do outreach and enrollment. Built relationships with other disability partners as part of that process, leading to positive outcomes.
- Capacity issues:
 - Waiting list for Home and Community Based Services (HCBS).
 - Resource poor.

- Budget cuts across the board in every agency.
- Things besides clinical services, UCEDDS could be thinking about:
 - Policy work
 - Research opportunities
 - Accessing Medicaid administration funds
 - Vermont is working with department of health and Medicaid offices to do 13 funded projects; use general fund dollars (people funded by the university) and match dollars that universities aren't accessing to work on different projects – OT, PT, and speech available for babies with low incidence disabilities; project goes through the College of Medicine; took three years to put this together and has resulted in a substantial amount of funding.
 - New Mexico is linked to clinical and direct services in four core areas: (1) birth to three, (2) autism, (3) FASD, and (4) medical fragile case management program and other small; working right now and renegotiating in the coming year; prove that we have state or other non-federal dollars that has been authorized as a match; huge boon for us but there's a big service delivery component and also allows for project development; it took us a couple of years but now we know how to properly document what we're doing; department chair wants to talk to us about how to do this across the department.

Tier D: Measuring Progress and Impact (Thursday 3:30-4:15 pm)

Facilitator acknowledged measuring progress and impact is difficult to measure and opened the floor to general questions.

Discussion and questions around measuring progress and impact with the following key points:

- Recommendation from several UCEDDs to be involved, make UCEDD known and educate about what UCEDDs do and their capacity, become involved on task forces, work intentionally with Developmental Disability councils.
- Don't provide too much free services that it costs over time, but be prepared to have to invest upfront to start the relationships.
- Start with small contracts and be able to deliver well on those and become a trusted resource.
- Set up clear expectations between partners.
- Leverage funds to implement changes that have been identified as need to be made in the system based on their assessment.
- Exerting some of our influence when and where we can.
- Assist with writing grants for state agencies as they often have little internal capacity to write discretionary grants or carry them out when they get them.
- Use UCEDD staff expertise to help rewrite state regulations and more progressive policies.

Much discussion was had over difficulties to include:

- Working in silos.
- Lack of resources and budgets.
- Uninformed legislature.
- State universities with non-compete laws.

- Politics with the University President / Office of Sponsored Projects.

Tier E: Collaborations & Next Steps (Friday 10:45-11:30 am)

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