



FULL COUNCIL MEETING

DRAFT MINUTES

Friday, November 17, 2023

10:00 AM – 12:00 PM

3839 North Third Street, Suite 306

Phoenix, Arizona 85012

Meeting held via teleconference

The full Council meeting of the Arizona Developmental Disabilities Planning Council (ADDPC) was convened virtually Friday, November 17, 2023, notice having been duly given. Present and absent were the following members of the ADDPC:

Council Members Present

Melissa Van Hook, Chair

J.J. Rico, Vice Chair

Monica Cooper

Meghan Cox

Kin Chung-Counts

Bianca Demara

Vanessa Felix

Ben Kauffman

Erik Jensen

Kathy Levandowsky

Kristina Lopez

Kristen Mackey

Janna Murrell

Gabriela Orozco

Vijette Saari

Mary Slaughter

Sophie Stern

Council Members Absent

Kelly Roberts

Mateo TreeTop

Council Staff

Jon Meyers, Executive Director

Marcella Crane, Contracts Manager

Michael Leyva, Contracts/Grants Coordinator

Jason Snead, Research & Communications Specialist

Lani St. Cyr, Fiscal Manager

Members of the Public/Guests

Jessie Barbosa, Arizona Dept. of Health Services (ADHS)

Emily Detwiler, ADDPC Intern

Jacy Farkas, Assistant Director, UA/Sonoran UCEDD

Holly Hulen, Associate Director, NAU/Institute for Human Development

Megan Woods, Arizona health Care Cost Containment System (AHCCCS)

Therese Yanan, Executive Director, Native American Disability Law Center

A. Call to Order/Welcome and Introductions

Chairperson Melissa Van Hook welcomed everyone to the Arizona Developmental Disabilities Planning Council (ADDPC or Council). The meeting was called to order at 10:03 AM. Introduction of Council members and roll call completed.

B. Minutes from September 22, 2023, Meeting

Chairperson Melissa Van Hook reviewed the September 22, 2023, minutes and asked the Council members if there were any comments or corrections to be made. As no changes were offered, a motion was called to approve the September 22, 2023, minutes. Sophie Stern made the motion, seconded by Vijette Saari. The motion carried.

C. Fiscal / Contract Update

Lani St. Cyr reviewed the ADDPC Financial Update and supporting documents. The following fiscal updates are as follows:

The Council has fully spent the FY 2021 award amount of \$1,535,342. ACL granted a one-year no cost extension for FY 2021 funds. This extension made the new obligation and project period through September 30, 2023, allowing an additional year for the work to be completed. The Council has until December 31, 2023, to liquidate FY21 funds and we have met that deadline.

The Council has received the full allotment for FY 2022 in the amount of \$1,500,930. This is level funding to FY 2021 excluding the Puerto Rico reallocation of \$34,412.

The Council has requested, and ACL has granted, a no-cost extension for FY 2022 extending the project period through September 30, 2024. The Council has fully obligated these funds and will need to complete the work by September 2024. There is approximately \$157,881 remaining to be liquidated.

The Council has received a third allotment for FY 2023 funding in the amount of \$398. This brings the current FY 2023 total amount to \$1,501,328. There is approximately \$41,109 remaining to obligate. The obligation and period of performance requirements are both through September 30, 2024, with the final report due by September 30, 2025.

The Council has received the first allotment for FY 2024 in the amount of \$196,284. The obligation and project periods are through September 30, 2025. The final report is due September 30, 2026.

ADDPC Additional Awards Update:

Access to Covid-19 Vaccines Funding: The Council has received an additional award in the amount of \$84,288 for COVID-19 specific projects. The funds are used to better understand the lived experiences of people with disabilities throughout the pandemic, including barriers to health services and access to the Covid-19 vaccine and information they need to make an informed decision. These funds are being tracked and reported separately. ACL granted a one-year no cost extension for using these funds. The funds needed to be obligated, and work was completed by September 30, 2023. NAU received the remainder of these funds to undertake further research and at this time of this reporting, they have fully spent the \$45,000 award for the project.

Expanding the Public Health Workforce within the Disability Network is the second allotment of Covid monies awarded to the Council. The additional award is in the amount of \$95,319 to expand the Public Health Workforce within the Disability Network. The funds are also being tracked and reported on separately. The obligation and project period are through September 30, 2024. The contract for this project has been awarded and the funds encumbered to UA Sonoran UCEDD for a collaborative project. Currently, the Council has not received any invoices for this project yet.

Council Funded Projects was the next presentation. All the proposals that were voted on at the last

Full Council meeting have been added to this sheet. We are following up with and expecting final invoices for all the projects that ended on September 30, 2023. These invoices were due by November 15, 2023, or 45 days after the contract end date. The only final invoice currently outstanding is from The Opportunity Tree. Staff will be reaching out to them and other contractors to ensure final invoices can be processed.

The final presentation is the Council's Budget Recommendation for FFY 2024. This sheet reflects the projects outlined in the FY 2024 Workplan as well as the funding that has already been approved in the prior years. The Column for FY 2021 funds has been removed and FY 2024 has been added. FY 2024 funds will be used primarily for projects to be decided on in the FY 2025 workplan. The Workplan Committee plans on meeting in early January to have further discussions on finalizing what will be budgeted with these funds.

D. Executive Director Report:

Jon Meyers reported on the following agenda items:

- **Covid-19 Public Health Workforce Development special funding:**
As previously stated, the Covid-19 Public Health Workforce Development funds of approximately \$95,000 will address the role of public health professionals in serving the aging population with I/DD. Public health professionals leading the project will be staff from the Regional Center for Border Health/Western Arizona Health Education Center (RCBH/WAHEC), located in Yuma, and the Sonoran UCEDD is acting as the fiscal agent for the contract. The contract took time to finalize, however, to date, six community forums have taken place, including 2 in Somerton (in Spanish), one in Yuma, one in Parker, one in Flagstaff, and one in Avondale, conducted in both English and Spanish. Focus groups are also being planned for the Tucson and Phoenix area. The focus groups will culminate in a final report that will include recommendations. The report is due by December 31, 2023. When the report is received, staff and the Systems Access and Navigation committee will review it and develop policy recommendations for the Council to consider.
- **Communications Director Position for the Council:**
Jon stated that he was worked with DES Human Resource to update the position of the Communications Director, especially to work with advocacy and self-advocates around the state. There are several layers of review and approval before the position can be posted externally and internally. Jon stated that he hopes to have the position filled in early 2024.
- **Council vacancies/renewals:**
Jon stated that he continues to be in communication with Governor Hobbs's administration and the Governor's Office of Boards and Commissions to ensure several vacancies are filled. The Council has several vacancies in mandated positions. Boards and Commissions is aware of the Council's vacancies, but the delay is largely due to the number of appointments the Governor must make to fill all the open slots on the state's hundreds of boards and commissions.

Mandatory memberships that are currently vacant include representatives from the Older Americans Act – which is the position filled by DES Div. of Aging and Adult Services (DAAS), Arizona Health Care Cost Containment System (AHCCCS), Arizona Department of Education (ADE), Arizona Department of Health Services (ADHS), University of Arizona Sonoran UCEDD, and a replacement for Mary Slaughter, which is a family member of someone who was institutionalized. Jon was able to clarify the meaning of that vacancy with the Council's technical assistance staff and it can be filled by a representative of someone who has lived in a group home. Jon will continue to update the Council as appointments are made.

- **Vaccine Equity Expert Panel:**

Jon will be on a panel with other experts, hosted with representatives from the Arizona Department of Health Services, Raising Special Kids, the Arizona Center for Disability Law, The Arc of Arizona, the Department of Economic Security, and the Statewide Independent Living Council to discuss seasonal fall vaccines and hesitancy for people with disabilities. This will be a discussion on all vaccines, not just Covid, and what lessons have been learned to continue outreach to vulnerable populations in our state. A flyer on the webinar is posted on our website. It is scheduled for Monday, November 20, 2023.

E. Committee Work Group Reports:

1. Grants:

Monica Cooper asked that staff present to the Council any committee updates. Lani spoke and stated the Grants Committee has not met since September and will be meeting in early 2024.

2. Work Plan:

Kathy Levandowsky stated the Committee met on November 3 to discuss the performance measures that all Councils are required to use to collect output and outcome data that is reported in the Program Performance Report, or PPR. Kathy said she found the guidebook on the performance measures interesting and that it is broken into two sections. There are measurements to report on self-advocacy projects and a second set of measurements to report on system change efforts. Kathy encouraged the Council members to review the guidebook. She found it very helpful when reviewing the Work Plan.

Kathy also stated that she has read ACDL's narrative reports on SEAP and found that project interesting. SEAP was just renewed for a third year and has been reporting really good data to the Council staff. Marcy stated that she is working with Jason Snead to have all narrative reports from 2023 and 2024 projects posted on our website. They are public documents, and the public and Council members can review who has been funded and how their project has been implemented.

3. System Access & Navigation:

Janna Murrell provided an update. She stated the committee has been meeting on a quarterly basis over the past 18 months to develop ideas for a web-based resource list for families that relocate to AZ so that they know how to find the right resources and agencies they need to contact depending on the age of their child with I/DD. The web-based resource list will be based on age ranges of the person with I/DD. We're moving ahead to the next phase, which is to gather resources for the aging/elder populations with I/DD. The primary work is undertaken by Amber Owens, who is an intern and initially started this project under Mary Slaughter's leadership. The committee is grateful for both Mary's and Amber's work on this project. At this point, we are finalizing the resources list for families, including a survey, and the next step is to upload the resources to the Council's website. More will be reported on at the next meeting as this is the primary focus of the committee's work. Janna also said that she and the committee members agreed to start every meeting with reviewing the Goal statement for System Access & Navigation to reorient everyone as to what we're all working toward. This will include a review of the objectives and activities. There is a lot of good work under this committee.

4. Meaningful Careers:

Melissa Van Hook provided the update on behalf of the committee. The Institute for Community Inclusion, University of Massachusetts Boston, has completed the final report of their Analysis of Vocational Rehabilitation Services for Transition-age for Youth with

I/DD in Arizona. The Meaningful Careers Committee will meet in December to discuss the report and make recommendations on the next steps.

The Center for the Future of Arizona is nearing completion of the Communities at the Center final report and once received it will be shared with the Meaningful Careers Committee for their recommendation on the next steps. Both the VR and the Communities at the Center projects will be presented at the Full Council Meeting in January 2024.

In the next month we plan to release two policy briefs. The first will be on Dual Enrollment to help smooth the transition to postsecondary education for students with disabilities. The second will be on College-Based Transition Services to help students with intellectual or developmental disabilities gain access to transition services on a college campus during their final two or three years of secondary education.

Melissa noted that she has spoken previously about the new easy read resource materials developed by Council staff but believes it is worth repeating. Six new resources were recently created to help individuals and families make informed decisions. The resource materials are part of the Pathways to the Future series:

- To increase awareness of education and training and participation in underutilized career paths for youth and young adults “Apprenticeships: Earn While You Learn” and “Career and Technical Education” were created. They were also translated into Spanish.
- To increase awareness of the career potential of individuals with I/DD and address systems change, “Imagine What I Can Do...” was developed; this document also shares information on Achieving A Better Life Experience, or ABLE, programs. To help address misconceptions about reduction in benefits for working adults with I/DD, “More Money. More Options. More Independence” was created.
- And to help youth with what their life will look like after high school (Will they go to college or work? Will they live on the own?) staff created a resource on “Transition Plans”. To help individuals who are exploring self-employment and entrepreneurship, we created “Starting Your Own Business”.

Any Council member who would like to receive copies of these resource materials should contact Mike Leyva.

During October’s National Disability Employment Awareness Month (NDEAM) the Council partnered with the DD Network, Vocational Rehabilitation, and the Arizona APSE Chapter on activities to highlight and promote disability employment. One of the activities included three training webinars that featured representatives from Vocational Rehabilitation and Assistive Technology for Employment and Independence. Ninety-eight (98) individuals attended the webinars and 95% of the follow-up surveys were positive. Melissa expressed a special thank you for all the partners represented on the Council who helped promote NDEAM and worked in collaboration with the Council. We sincerely appreciate the assistance and participation of your dedicated staff.

5. Behavioral Health & I/DD:

Jason Snead provided the update. Since the last Council meeting, at which the Council approved Noble Predictive Insights (NPI) design to create a survey to gather data regarding individuals with disabilities, caregivers and family members experiences around Arizona crisis and behavioral health systems, NPI has provided the behavioral health and I/DD committee core group members with a draft of the questions for them to make suggestions for edits and revisions. The core group has made those revisions and edits and will be meeting with the NPI team at the end of the month

to finalize the survey instrument. A formal contract has not been executed until all questions have been addressed.

F. Community Partner Presentation:

The Council invited Therese Yanan, Executive Director for the Native American Disability Law Center (NADLC) to give an overview of NADLC and the work it undertakes in the Four Corners region of the states of AZ, CO, NM, and UT, serving both Navajo and Hopi Tribes.

In her presentation to the Council, Therese gave an overview of the following:

- A history of how the NADLC came about and was federally recognized under the Protection and Advocacy (P&A) section of the DD Act. This was an evolution going back to the mid-1990s. Therese Yanan has been working in this community and in some capacity with NADLC for several decades. She is truly committed to the work and to the Tribal communities and people she admires.
- Every five years, NADLC must complete a needs assessment that is comprised of Talking Circles and written survey questions provided to the community in both hard copy and internet based. Those are also circulated to service providers as well as previous and current clients and/or anyone who has been in contact with the NADLC services. NADLC also reviews previous legal cases that were not taken up by any of the attorneys to conduct further outreach efforts.
- In terms of staff, there are three attorneys as well as herself. Therese is an attorney in Utah, Arizona, New Mexico, and can bring cases within Navajo and Hopi legal systems. As the Executive Director, she does not keep a full legal caseload. There are also two Advocates and one community-government liaison, Hoskie Benaly, who is a Navajo Elder and an individual with a disability. Hoski is also president of the Navajo Advisory Council on Disability and a member of the National Council on Disabilities.
- Through this large community assessment, NADLC identifies top issues to address over the next five years, which is a very similar process to what the Council does and the issues overlap. For instance, both organizations are addressing issues of abuse and neglect. NADLC monitors congregate care facilities and group homes on the Navajo Nation and also detention facilities. The NADLC board has recently asked staff to expand this monitoring to day programs so that there is a constant presence to identify a serious situation.
- This issue has also led to working with both the Navajo Nation and Hopi Tribal Councils to help develop specific ordinances to address abuse and neglect of adults with disabilities and other vulnerable adults. The Navajo Nation adopted the Adult Protection Act several years ago; the Hopi Tribe has been in legal consultation for several years and thus an agreement is not completed. Once completed, this will give some guidance and clear structure on what happens to reports on abuse and neglect so that the victims receive the proper care and treatment, and the perpetrator is held accountable.
- Another key area that is addressed is the lack of transportation for individuals and families and access to appropriate services that parents want for their children with disabilities. This includes ensuring and working closely with both the tribal and state VR programs that can benefit many of the people with disabilities to find meaningful employment opportunities. Therese stated there is a lack of referrals from VR programs, even though NADLC informs them of the need and potential clients.

- During the Covid-19 pandemic, the reservations were cut off from the world as everyone else was. This was difficult because of the lack of reliable internet services in some of the more rural areas of the tribal reservations. The more populated communities such as Gallup, NM, have internet, but it's not safe to assume everyone has internet access.
- A lot of what NADLC does, aside from legal work, is a combination of Community Education, Individual Advocacy and Systems Advocacy. Therese stated she tries to be strategic, as NADLC is a small, funded program. So, they try to take on individual cases with a focus on impacting and benefiting the system for the larger good. All this work takes a lot of time. As an example, NADLC sued the Bureau of Indian Education twice over their failure to properly serve students with disabilities. When NADLC is made aware of those cases, one of the first things to do is determine what are the systemic issues that need to be changed. The hope is by addressing those two cases with the Bureau of Indian Education, a broader impact will be felt by even more students.
- Like Supported-Decision Making (SDM), Therese helped the Navajo Nation change its previous guardianship act which didn't provide any meaningful due process, a concept that the Navajo Nation has adopted within their court system. With the assistance of NADLC, adherence to the guardianship act is now mandated. There is also an alternative to guardianship, called a Court-Appointed Representative, similar to a Power of Attorney. This representative will be identified by the family to help make important decisions, related to such things as medical care, for the individual with a disability who needs someone to assist them in communicating their preferences and in providing consent. The person with the disability is not incapacitated but needs that assistance and someone they know who they trust. This is a form of legal protection for them and since the concept is fully around the family that will help decide who is the representative, it also coincides with the traditional cultural approach.
- A key point Therese stated is that the Tribal communities are Sovereign Nations, and they have the capacity to develop their own legal structure. The Navajo Nation has a Navajo Nation Code which is similar to, but not as expansive as, any other state code. The Hopi Tribe has a set of ordinances that are like those in many tribal communities around the country and there are various resources to help them develop codes and statutes that will guide their governments. Because of the unique federal-tribal relationships, tribal communities have sovereign status; state and federal laws do not necessarily apply on tribal land. For example, people may assume the Americans with Disabilities Act (ADA) applies on the reservations, and many attorneys will tell you it does not. This goes back to the basic tenets of federal Indian law and there has to be very clear intent when the federal government is making a federal law – does it apply to the Tribal communities around the country?
- Therese values her partnerships with the Arizona Center for Disability Law, the Council and their counterparts in New Mexico, Utah and Colorado. She has lived and worked in this area for close to 30 years and is eager for any Council member to visit her and the tribal communities. There is a NADLC office in Flagstaff, however, Therese is in Aztec, New Mexico.

Meghan Cox stated she represents tribes in her public affairs work and would like to connect with Therese. Melissa and other Council members expressed their appreciation for Therese's presentation and dedication to the tribal communities.

G. Announcements:

Sophie Stern stated that she will be performing a dance solo with Empowered Theater & Arts, on November 17 & 18 at Paradise Valley Methodist Church. She invited Council members and staff to attend.

Meghan Cox stated that she saw Sophie's performance and it was really great to see her perform.

Kristen Mackey stated Arizona Vocational Rehabilitation will have federal monitors February 26-29 to meet with various groups. Her office is coordinating the visit, and she will be reaching out with more information.

H. Call to the Public:

Jacy Farkas, with the UA Sonoran UCEDD, said they received extra funding from the National Association of Universities on Excellence in Disabilities for a statewide vaccine clinic. Anyone who is interested can contact Jacy.

I. Adjourn:

Chairperson Melissa Van Hook adjourned the meeting at 11:33 AM.

Dated this 27th day of November 2023
Arizona Developmental Disabilities Planning Council