



FULL COUNCIL MEETING

DRAFT MINUTES

Friday, April 19, 2024

10:00 AM – 12:15 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, April 19, 2024, 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

Jessie Barbosa

Monica Cooper

Kin Chung-Counts

Bianca Demara

Vanessa Felix

Kathy Levandowsky

CJ Loiselle

Kristen Mackey

Janna Murrell

Kelly Roberts

Vijette Saari

Rana Simms

Mary Slaughter

Mateo Tree Top

Council Members Absent

Meghan Cox

Erik Jensen

Kristina Lopez

Gabriela Orozco

Sophie Stern

Council Staff

Jon Meyers, Executive Director

Marcella Crane, Contracts Manager

Michael Leyva, Contracts/Grants Coordinator

Sarah Ruf, Communications Director

Jason Snead, Research & Communications Specialist

Lani St. Cyr, Fiscal Manager

Members of the Public/Guests

Lionel Delgado

Jacy Farkas, UA/Sonoran Center for Excellence in Disabilities (pending Council member)

Brianna Farmer, DES Legislative Liaison

Jacqueline Gonzales

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 10:05 AM. Introduction of Council members and roll call completed.

B. Minutes from January 19, 2024, Meeting

Chairperson Melissa Van Hook reviewed the January 19, 2024, 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 January 19, 2024, minutes. Vijette Saari made the motion, seconded by Kin Counts. The motion carried.

C. Fiscal / Contract Update

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

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. 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 30, 2024. There is approximately \$23,171 remaining to be liquidated.

The Council has received an additional allotment of FY 2023 funding in the amount of \$398. This brings the current FY 2023 total amount to \$1,501,328. The Council has fully obligated these funds. There is approximately \$705,621 remaining to be liquidated. The obligation and period of performance requirements are through September 30, 2024. The final report is due September 30, 2025.

The Council has received the third allotment for FY 2024 in the amount of \$200,476 bringing the current award amount to \$711,770. The obligation and project periods are through September 30, 2025. The final report is due September 30, 2026. The Council has not received the final award for FY 2024 yet, but it should be at level funding.

Next, an update was given on the additional awards the Council has received.

The Council received \$84,288 for COVID-19 Vaccine specific projects. ACL granted a one-year no cost extension for these funds. The funds needed to be obligated, and work completed by September 30, 2023. The final report was due by the end of January 2024. The Council has spent \$82,809 and reverted \$1,479.

The Council received an additional award in the amount of \$95,319 to expand the Public Health Workforce within the Disability Network. These funds are being tracked and reported on separately. The obligation and project period are through September 30, 2024. The contract for this project has concluded. The Council has received and paid all invoices for the total amount of \$95,319.

The Council Funded Projects sheet was reviewed. This sheet shows all projects currently funded by the Council. This sheet has had very few changes and no new contracts since the last Executive Committee meeting. Staff are following up with any outstanding invoices.

The Budget Recommendation document was then reviewed. This sheet reflects the projects outlined in the FFY 2024 Workplan as well as the funding that has already been approved in the

prior years. FFY 2024 funds will be used primarily for projects to be decided on in the FFY 2025 workplan. Currently, there is an anticipated shortfall of \$17,672 for FFY 2024 funds. However, there are several new RFGA projects that have not been funded yet and this leaves some flexibility if the Council is unable to award projects at the levels that have been budgeted for.

D. Executive Director Report:

Jon Meyers reported on the following agenda items:

- Council vacancies/appointments/re-appointments:
Jon stated that he is pleased to report that most of the appointments to the Council have been finalized by the Governor's Office of Boards and Commissions. These include the following mandatory appointments: DES Division of Aging and Adult Services (DAAS), which fills the Older Americans Act requirement, Arizona Health Care Cost Containment System (AHCCCS), and Arizona Department of Health Services (ADHS). Several re-appointments of Council members were also approved.

We are still waiting on the following final appointments: Arizona Department of Education (ADE), University of Arizona Sonoran UCEDD (Jacy Farkas, the new Sonoran Center executive director will fill this position), and a replacement for Mary Slaughter, who fills the position of a family member/caregiver of someone who was formerly institutionalized. As a point of reference, 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 and will reach out to several Council members this summer whose membership expires. There is a process to re-apply if interested.

- Covid-19 Public Health Workforce Development special funding:
As previously stated, public health professionals from the Regional Center for Border Health/Western Arizona Health Education Center, located in Yuma, led a research project on where there are gaps in services for the aging population with I/DD and where supports for their families and caregivers need improvement. The research involved several focus groups with analysis of the findings. A draft report was submitted, and Jon has provided feedback to RCBH to make several changes before it can be released. When the report is finalized, it will be reviewed by the System Access and Navigation Committee for any policy recommendations that the Council may consider.
- Bridging Disability & Aging Community of Practice:
Jon also said Arizona is now one of 17 states funded by the National Association of Councils on Developmental Disabilities (NACDD) and ACL through a national Community of Practice addressing the gaps in services and supports for the aging community with I/DD. Our application was recently approved, and this is a collaborative approach, with many stakeholders involved.

Jon stated he would like to encourage other agencies/organizations to join the Community of Practice and if anyone is interested or knows of someone, to contact him directly. Jon said the CoP recently met and the initial action item is to develop a work plan. There is small funding to support the work, which is \$5,000 per year for three years. through the end of FFY 2026

- Legal Options Manual Update:

Jon presented the proposal by the Sonoran Center to update the Legal Options Manual. They are requesting \$21,279. The Legal Options Manual was last updated in 2016 and it is a highly sought after resource by family members and organizations that request hard copies from the ADDPC. The 2016 version is currently on our website and is outdated.

Jon stated there are several changes to make, such as adding a chapter on Supported Decision-Making and updating the legal forms from the current Arizona Attorney General's Office. The Sonoran Center will subcontract most of the work to Disability Rights Arizona, and the updated manual will be available in plain language and in Spanish. The timeline is also adjusted for the work to be completed by December 30, 2024.

J.J. Rico appreciates the Council consideration to update the manual. Kathy Levandowsky asked if the Legal Options Manual will be translated into other languages? J.J. stated at this time no, but that they will track the number of requests from the community that ask for the document in another language because of the cost that is involved.

Chairperson Melissa Van Hook asked the Council members if there were any further comments. Hearing none, a motion was called to approve the Sonoran Center's proposal for updating the Legal Options Manual in the amount of \$21,270. Mary Slaughter made the motion, seconded by Janna Murrel. J.J. Rico abstained. The motion carried.

- 2024 Disability Policy Seminar, April 8-10, Washington D.C.:
Jon stated that Disability Policy Seminar was attended by Michael Leyva and Council member Vijette Saari and himself, with other advocacy groups from Arizona. The Arc of Arizona, The Arc of Tempe, and both UCEDDS sent representatives, as well.

The final day included visits on Capitol Hill, where Arizona's delegation was able to meet with 10 out of 11 of our congressional offices. Jon thanked Michael Leyva for setting up those meetings and for everyone splitting up their time to meet our congressional staff.

Vijette said it was a wonderful opportunity to represent Arizona and the Council and to meet with other organizations from Arizona. She was impressed with the self-advocates who asked policy questions and the impact of funding on their personal lives during those congressional meetings.

Jon said having Vijette attend and to personally speak and advocate was a tremendous advantage. Vijette stated since attending, Representative Gosar's office followed up with her and they recently met in Lake Havasu City to have further discussions.

Jon stated this is a wonderful opportunity for Council members to attend. The 2025 Disability Policy conference is scheduled for April 7-9. More information will be relayed next year.

E. Committee & Work Group Reports:

1. Grants:

Marcy Crane covered three work items. The first was the annual Conference and Training Sponsorship grant solicitation. The grant notice was released in February and 10 organizations applied for funding. Marcy stated that she is working with an evaluation committee to review the proposals. Any final recommendation to the Council will occur in June 2024.

Second, Marcy noted the grant notice for Internet Safety Training is currently open. Applications are due April 25, and there is \$100,000 available to apply. Multiple awards are expected, and the Council will approve any applications in June 2024.

The third grant project will address abuse and neglect prevention, identification, and reporting. Jon and Marcy are in the process of finalizing the scope of work and the dollar amount. Marcy will release this grant notice in June for the Council to approve any awards in September 2024.

Marcy also stated that there are several current projects that were notified of their renewal status, including Supported Decision-Making, Self-Advocacy, and the three funded projects under the Pregnancy/Parenting grant. Each of these will apply for second year funding.

NAU/IHD submitted a proposal for Assistive Technology to support SIP-C college students. The proposal is for \$50,000 and staff is reviewing this proposal.

2. System Access & Navigation:

Janna Murrell provided an update. She stated the committee last met on March 12, 2024. During that meeting, Amber Owens, a former ADDPC intern, described the changes made to the web-based resource guide for families living in or relocating 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/family member with I/DD. Amber also updated the survey based on the committee's feedback. The next step they discussed is to pilot the "how-to guide" and to work with Sarah to incorporate it on the Council's website.

Janna then restated that the committee would review the final report from the Regional Center for Border Health, as well as the Bridging Disability and Aging Community of Practice. The final report should inform both committees' work.

Kin Counts asked if the "how-to guide" would have a mobile app? Sarah said she will look into that, but the first step is to make sure it is accessible on our website before creating a user-friendly app.

3. Meaningful Careers:

Melissa Van Hook provided the update. The Meaningful Careers Committee met on April 2 and reviewed the FFY 2024 Work Plan. We are in the second half of the federal fiscal year and there is quite a bit of work that needs to be completed by September 30.

During the meeting the committee also discussed new projects that may be funded in the new fiscal year. Michael Leyva is reaching out to organizations for additional information to help the committee make its recommendations. Members are excited about the new webinar series, "Creating a Life Full of Possibilities!" The five webinars will kick off on May 8, 2024, with a webinar each month through September 2024. The first session is "Person Centered Planning: The Steps to Your Future" and will feature Cheryl Bates-Harris with the National Disability Rights Network. Cheryl has more than 30 years of experience working with people with disabilities and has conducted nationwide training for the Protection & Advocacy organizations, Client Assistance Programs, and community organizations. Cheryl is adamant that work is the only route out of poverty, and everyone should be able to find real work in the community at real wages. More information will be coming soon. Melissa said she encourages Council members to attend.

4. Behavioral Health & I/DD:

Jason Snead provided the update. The Behavioral Health and I/DD Committee was formed in order to develop the crisis report distributed by the Council over two years ago. With guidance from the committee, a core team was formed to help address some of the issues in the report and meet with state agencies such as the Division of Developmental Disabilities (DDD) and other Managed-Care Organizations (MCOs) from around the state.

Jason mentioned some of the accomplishments of the last two years, one of which is the Augmentative Assistive Communication (AAC) device training facilitated by DDD to providers and first responders because of a letter written by the core team to leadership at AHCCCS about the illegal removal of AAC devices in behavioral health facilities and group homes.

Because of the lack of data regarding individuals with I/DD in the Arizona behavioral system, in 2023 the Council approved funding for Noble Predictive Insights (NPI) to design a survey that would gather data regarding the experiences of individuals with disabilities, caregivers, and family members interacting with Arizona's crisis and behavioral health systems. The survey was completed in January. During the meeting, Jason gave a presentation regarding the survey's findings, with 178 respondents filling out the survey. The information received and analyzed by NPI has two sections, individuals who have not experienced crisis/behavioral health system and those who have.

The key takeaways were: Among those who did not report experience with behavioral health crisis services, many were worried that first responders or other personnel would not have the right training to handle their situation.

Among those who did report experience with behavioral health or crisis services, many did not have a positive experience. People who learned preventative strategies from their behavioral crisis providers benefited from them. Talking to a DDD coordinator helps. Many members of the I/DD community haven't used behavioral health/crisis services, and many are worried about what would happen if they did. The I/DD community members who have experienced behavioral health services have significant frustrations.

There are recommendations for the core team to consider. One suggestion is doing an independent audit of the crisis/behavioral health system. The other suggestion is creating a task force which would seek legislation to improve these systems.

5. Work Plan:

Kathy Levandowsky stated the Committee met on March 8, 2024. Staff provided a brief wrap-up of the FFY 2023 work plan and current updates to the FFY 24 annual work plan. The next meeting is May 17, 2024. Kathy also thanked staff for adding the grantees' narrative reports to the Council's website. Marcy stated that Sarah will be updating the website so that it will be easier to navigate and find information.

F. Grantee Presentations:

Institute for Human Development, Northern Arizona University – Supporting Inclusive Practices in Colleges (SIP-C).

Sakenya McDonald and Tricia Carver presented an overview of the SIP-C project. SIP-C, or Supporting Inclusive Practices in Colleges for students with I/DD, was funded by the Council for four years. The purpose of SIP-C was to create and sustain a model for transitioning age youth, between the ages of 18-26, who wanted to go to college, but needed support to succeed. The

program focused on youth primarily in Northern Arizona, but in the last year expanded SIP-C into Yuma County.

SIP-C strived to improve the outcomes for individuals with I/DD participating in post-secondary education experiences by providing them with employment coaching and peer mentors who utilize person-centered planning. The project promoted full inclusion in the post-secondary education experience and encouraged independent living and gainful employment. The vision was to ensure individuals with I/DD can self-determine and advocate for their education and employment goals and have consistent access to support in inclusive, authentic and appropriate environments. The ideal result would be that individuals with I/DD will achieve improved transition outcomes, and they will also achieve advanced educational experience.

In year four, Sakenya explained that the model needed to be sustained and expanded. IHD chose Yuma County for expansion and began working closely with Arizona Western College (AWC). The similarities between Northern Arizona and Yuma County were a good fit for SIP-C to expand. The staff at AWC were helpful to NAU because they were able to provide unbiased feedback and a fresh perspective on the model program and what changes to make to the ten distinct strategies and workbook that would be tailored for under/served areas.

Feedback and communication from the SIP-C students and school administrators were addressed by NAU. The resulted in specific changes that are very helpful to sustain the project. An example of positive change that NAU implemented was to have a Student Advisory Board of SIP-C students who could communicate about their lived experiences and collaborate with their peers. Many times, they could not attend the larger NAU advisory board, but having a self-advocacy group was instrumental in hearing their direct feedback.

NAU also changed how it conducted professional development and training of college staff. In the past, it was typically NAU conducting the training on SIP-C purpose and goals, having staff understand the needs of students with I/DD in colleges, etc. Now the narrative is reversed and students and local partners are the community and campus experts, informing NAU at a professional level as to what would work in some areas or instances and suggesting any changes that NAU would need to be aware of. This has been helpful to NAU, to hear from the college campuses and community partners who are experts with lived experience, as well.

The third broad area that NAU changed was how it collects, analyzes, and uses all the data it is tracking and receiving from experts. By using the SIP-C student advisory board, as well as the core team, they developed an interactive transition workbook for those communities that are more rural and unserved by transition age services. This is something that can be accessible on larger scale, for families/caregivers, VR specialists and teachers.

Data from the SIP-C students who are surveyed show that 86% of students that join SIP-C set personal goals more frequently; 66% indicated that they set academic goals more often; 73% felt more confident to attend classes by themselves; and 66% are more confident speaking to a teacher directly when experience a problem. Sakenya also highlighted success stories of SIP-C students.

She ended with where to find more information on SIP-C on NAU/IHD's website.

Janna Murrell stated Raising Special Kids is hosting a transition institute for families, youth and young adults on Saturday, July 13, and invited Sakenya to present and share the workbook with attendees.

Michael Leyva and Marcy Crane thanked Sakenya and her team for the great work they did over four years. They plan on sharing this project through the ITACC website, sharing best practice projects funded by the Council.

Mary Slaughter asked if the SIP-C model can be replicated for older adults with I/DD who have an interest in lifelong learning experiences? Sakenya said yes, and that they have identified a college system in California that is focused on professional credentialing in certain areas or certificates, but that 55% of their population in this project are 65 years of age or older. Sakenya further stated that she believes lifelong learning is essential especially for our elderly and aging population. Not only does it continue their skills, but it also can minimize things such as loneliness and feelings of isolation. It keeps them engaged; it helps them have that multi-generational engagement at times. She is more than happy to continue this conversation with Mary.

Kathy Levandowsky asked if there is a section in the workbook for families/caregivers that can help them with transition. Tricia Carver said yes, there are specific sections for them depending on where the students are in school (already in college or still in high school).

Kristen Mackey asked if there is a section in the workbook on Vocational Rehabilitation, and Tricia said there is.

Melissa thanked both Sakenya and Tricia for their presentation.

The next presentation was given by the Sonoran Center for Excellence in Disabilities, University of Arizona – Elevating Refugee Perspectives about Access to Disability Services in Arizona.

Julie Armin and Jacy Farkas presented this project. Julie began the presentation by thanking the team of researchers and their community advisory board members. Julie also thanked the Council for allowing additional time to complete the data collection and analysis.

The final title of their report, released in March 2024, is “Elevating Refugee Perspectives about Access to Disability Services in Arizona”. The goal of this project was to understand the experiences of the diverse community of refugees with disabilities in Arizona. Researchers explored ways that the disability service system may not be accessible to refugees. They also identified ways to make the service system more accessible. Researchers at the University of Arizona Sonoran Center for Excellence in Disabilities reviewed accessibility policy (laws) for disability and refugee service agencies in Arizona and the U.S. Researchers asked refugees, resettlement workers, and disability service providers in Arizona about their experiences. Researchers used a method called Group Concept Mapping to sort data and find what they consider most important. Finally, researchers also did in-depth interviews with refugees with disabilities and their supporters to learn about their lived experiences.

Below are barriers/problems mentioned by the participants who shared their ideas:

- Refugees and their families may not be aware of individual rights and opportunities – for example, the opportunity to stay in school beyond the age of 18 if you have goals to be achieved.
- Inability to get the support needed to pursue education/employment.
- Lack of language interpretation for people with disabilities and their supporters.
- Interpreters were not provided or were provided in the incorrect language or dialect.
- Families are not aware of services because of service system issues. Examples include the person with a disability not being included in meetings with providers.
- Families disagree with the goals that education staff have set for their child with a disability.

- The long length of time to get services. The disability service system may not recognize the importance of the community/collective. Clients may consider the well-being of their families or communities more important than the individual's needs.
- For children under 18, there was confusion about whether parents could be paid as caregivers. It may be important to the family to provide care instead of a Direct Support Professional because the family knows the person best.

The report also highlighted recommendations for fixing these issues. They include:

- Ensuring language access, including enough funding and oversight to make sure policies are followed. Consider new approaches such as a free language line that provides interpretation any time.
- Providing reliable transportation that is on time and accessible. People should also be able to use transportation services in their own language.
- Creating peer support programs for refugees with disabilities and their families.
- Improving primary and secondary schools' ability to engage with refugee families. This can be done by facilitating appropriate testing and support for students.
- Training disability-focused refugee case managers who have knowledge of specialized disability systems.
- Employing a "Developmental Disability Navigator" to provide ongoing advocacy.
- Identifying and educating "gatekeepers" to connect refugee communities with disability services. Gatekeepers may be language interpreters, health care providers, or other community leaders.
- Timely and linguistically appropriate diagnosis and assessment for refugees with disabilities.
- Providing education to refugee families about the expectations for self-advocacy in the U.S., including the focus on individual rights within the disability service systems.

Both Dr. Armin and Jacy suggest that these broad recommendations should be put into practice with many agencies, providers, and organizations working together while considering service availability, accessibility, and quality.

Both Melissa and Kathy thanked UA for this report and their hard work. The report will inform the Council on how they can support the recommendations.

G. Announcements:

None.

H. Call to the Public:

Lionel Delgado stated that he would like to ensure that for Disability Awareness Month in 2025, that a proclamation from the Governor's Office be shared with ADE and with local schools so that they are aware of the meaning behind this celebration.

I. Adjourn:

Chairperson Melissa Van Hook adjourned the meeting at 12:15 PM.

Dated this 25th day of April 2024
Arizona Developmental Disabilities Planning Council