



FULL COUNCIL MEETING

DRAFT MINUTES

Friday November 22, 2024

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 22, 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

Meghan Cox

Bianca Demara

Vanessa Felix

Erik Jensen

Kathy Levandowsky

CJ Loiselle

Janna Murrell

Gabriela Orozco

Kelly Roberts

Vijette Saari

Mary Slaughter

Rana Simms

Sophie Stern

Mateo TreeTop

Council Members Absent

Vanessa Felix

Kristen Mackey

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

Ryan Barry, Project Director for Arizona Achieve, The Arc of Tempe

Le Ann Fuller, Council applicant

Sey In, Staff Attorney, Disability Rights Arizona

Melanie Mills, Executive Director, The Arc of Arizona

Ruth Ann Strom, Executive Director, The Arc of Tempe

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 20, 2024, Meeting

Chairperson Melissa Van Hook reviewed the September 20, 2024, minutes and asked the Council members if there were any comments or corrections to be made. Kathy Levandowsky asked that two changes be made to the minutes: 1) On page 5, reword the last sentence on the bottom of the page; 2) a spelling change on page 10, correct the word participants located under the Meaningful Careers committee report out. Staff will make the changes. A motion was called to approve the September 20, 2024, minutes, as amended. Monica Cooper made the motion, seconded by Mary Slaughter. 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 ADDPC Financial Update showed the Council has fully spent the FY 2022 award amount of \$1,500,930. The Council had requested, and ACL granted a no-cost extension for FY 2022 extending the project period. The Council has fully obligated and spent these funds. The work has been completed by the extended September 30, 2024, deadline.

The Council has received a total allotment of \$1,501,328 for FY 2023. The Council has fully obligated these funds. A no-cost extension for the period of performance has been granted and now runs through September 30, 2025. There is approximately \$117,470 remaining to be liquidated.

The Council has received a fifth allotment for FY 2024 in the amount of \$3,482, bringing the award amount to \$1,500,684. The obligation and project periods are through September 30, 2025. There is approximately \$4,350 remaining to be obligated.

The Council has received the first allotment for FY 2025 in the amount of \$332,208. Currently we are estimating the award total to be at level funding, but that may change. The obligation and project periods are through September 30, 2026. The final report is due January 28, 2028.

The Council also 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 project report was due October 31, 2024, and was submitted. The financial report is due by January 31, 2025. The obligation and project period were through September 30, 2024. The Council has received and paid the invoices for the full grant amount of \$95,319.

Next, the Council Funded Projects sheet was reviewed. This sheet shows all the current projects funded by the Council. All the proposals voted on at the September Full Council meeting are now reflected on this sheet. Staff is following up with any outstanding invoices for the contracts that ended in September.

Finally, the Budget Recommendation document was reviewed. This sheet has been updated to reflect the projects outlined in the FY 2024, 2025, and 2026 Workplans as well as the funding that has already been approved in the prior years.

FY 2025 funds will be used primarily for projects to be decided on in the FY 2026 workplan. Currently, there is an anticipated surplus of \$227,000 for FY25 funds, which may be needed if there is reduced funding. The administrative budget has been increased to reflect the work to be done with the Comprehensive Review and Analysis.

D. Executive Director Report:

Jon Meyers reported on the following agenda items:

- **FFY 2025 and FFY 2026 Annual Work Plans:**
Jon stated that the Administration on Community Living (ACL) reviewed our FFY 2025 and FFY 2026 Annual Work Plan and approved both work plans. There were no changes to make. The FFY 2025 Annual Work Plan will take effect October 1, 2024, through September 30, 2025. FFY 2026 is conditionally approved by ACL and updates can be made next August 2025. Jon thanked staff and Kathy Levandowsky's committee for providing input during multiple reviews.
- **FFY 2023 No-Cost Extension Request:**
Jon stated he was notified by ACL of their approval of the Council's request of a no cost extension on the FFY 2023 award. This approval will ensure those funds can be liquidated by September 30, 2025. As a reminder, Lani has identified a few projects that will support this request, such as the Data Hub/Community Index. The federal extension will allow Dr. Alex Kurz to analyze the DDD data he has been provided and upload it to the Data Hub, as well as update U.S. Census data. Dr. Kurz's contract is approved as a no-cost extension through January 31, 2025.
- **FFY 2025 Federal Grant Award:**
The Council has received notification of the first allotment of the FFY 2025 award. Jon also stated that the current Continuing Resolution that Congress passed in September will expire on December 20, 2024. Without further action on congressional budgets, we're not able to predict the next steps. Jon will update the Council as updates are provided.
- **Impacts of the 2024 General Election:**
Jon briefly commented on the impact the next administration will have on the work of the Councils, Protection & Advocacy organizations, and the UCEDDs. The ADDPC is not a political entity itself, thus it relies on partners such as the National Association of Councils on Developmental Disabilities (NACDD) to lobby on behalf of the Councils. There are other disability advocacy groups that will also be watching what changes the new administration will impose. The proposed elimination of the Department of Education could have grave consequences on all students with IEPs, funding for schools, and grants and scholarships. There might also be proposed changes to Medicaid.

As the next year begins, the focus of what will be proposed - budget cuts, changes in regulations, changes in federal agencies and departments - will require all of the disability partners to work together to educate our federal legislators about the detrimental impact these proposals could have on families.

Jon also stated that Arizona's state legislature will require our time to spend with those that were newly elected and begin to meet with them and share the work of the Council. The state budget is uncertain at this time and it is unclear how that will impact the work of the state DD agency's ability to support programs for families in need.

As a staff, we will continue to do our part and work ahead in these uncertain times.

E. State Plan Development – 2027-2031:

Jon stated that staff has been in discussion with NAU/IHD to conduct the first phase of the Council's Five-Year State Plan Development, which is the Comprehensive Review and Analysis, or CRA. The CRA is an accumulation of data collected from multiple state and federal sources and provides a portrait of Arizona's disability population. Required data is collected from key areas such as Quality Assurance (safety and training in leadership for self-advocates), Healthcare, Employment, Informal and Formal services and supports, Self-advocacy and Interagency Initiatives. IHD will undertake this work in three key tasks to create a final report of the CRA no later than December 31, 2025. The First task is data collection in key areas. The second task will be releasing two surveys: one survey to gather input from individuals with disabilities and their families/caregivers, and a second survey to community organizations, stakeholders, and service providers. The third task will be six to eight town halls/community conversations throughout Arizona. Focus areas will be un/underserved areas of the state, tribal and rural communities, and urban areas. Information gathered from the public will be used to augment the raw data collection and to help the Council understand the gaps and barriers individuals with disabilities and their families face.

NAU/IHD's proposal includes a timeline with key target dates for each task, with multiple reports provided to the ADDPC and to a newly formed ad-hoc State Plan Development Committee. NAU/IHD will also meet frequently with staff and the ad-hoc committee to keep them apprised of their work and to seek assistance when needed. A final comprehensive CRA report will be submitted as early as September 30, 2025. The requested amount to support Phase 1 is \$ 98,439 and 25% match is provided in the amount of \$32,810.

Kathy asked if raw data will be provided to the ADDPC if Congress does not authorize future federal funding to support the Councils. Marcy stated yes that all work up to the end of the contract period will be provided to the Council.

A motion was made to approve the proposal by NAU/IHD to support Phase 1, the CRA data collection. Vijette Saari made the motion, Sophie Stern seconded the motion. Kelly Roberts abstained from voting. The motion carried.

F. Committee & Work Group Reports:

1. Grants Committee:

Monica Cooper stated that the committee has not met since September and there are no updates.

2. System Access & Navigation:

Janna Murrell provided a summary of the committee's work. The committee most recently met on September 17, 2024, and discussed the "How-To-Guide" that is available on ADDPC's website. The Guide is a tool for any family to use on what are the best resources and agencies to contact at any point of your life or for the person with a disability. The committee will continue to add resources and links as they come across, especially resources to assist the aging population with disabilities.

Janna stated that the committee will continue to be focused on Access to the Systems of Care, Unserved Communities and how to support the aging population with disabilities.

Monica asked if the How-To-Guide is in plain language. Sarah stated that most of the information is available in that format. Sarah said that she receives many calls from families that have just moved to Arizona, and they do not know where to start to find support and care for their child with a disability. The How-To-Guide is a great way for a family to begin to navigate Arizona's DDD system. Sarah also stated that she and Jason will host once a month a Walk-In Office Hours for anyone who wants additional information. They can meet with Sarah and Jason and hopefully find meaningful solutions to the barriers families may be facing. Melissa loved this idea and asked that they track this data and report it back to the Council.

Kin Counts asked if the How-To-Guide is also available as a handbook. She said that as individuals with disabilities get older, they may not be as tech savvy to find the information they need. Mary Slaughter agreed with this comment and said that is one of the areas the Community of Practice committee is looking into and how to address.

3. Meaningful Careers:

Melissa Van Hook provided the update. Staff completed a write up of the 14 Meaningful Careers activities which were completed in fiscal year 2024 for the Program Performance Report (PPR). Jon and Marcy are reviewing and editing the write up and will include it in the Council's overall 2024 PPR submittal to the Administration for Community Living.

In fiscal year 2025, Council staff are exploring conducting a leadership development and training program for individuals with intellectual and developmental disabilities and family members with information and skills to become leaders and advocates for systems change in Arizona. The intent is to develop and support capacity building and systemic change to increase inclusion and involvement of people with I/DD in their communities through the promotion of self-determination, independence, and dignity in all aspects of life. If everything falls into place, the program will kick off with an in-person session for up to 30 individuals in March 2025, deliver 7 virtual sessions led by national experts each month through August 2025, and have a second in-person session for the leadership training and to "put all the pieces together."

ADDPC is generating lots of enthusiasm and support for Think College thanks to the Supporting Inclusive Practices in College project with the Institute for Human Development at Northern Arizona University. That project has spawned a new collaboration of inclusive postsecondary education programs for students with intellectual and developmental disabilities. A meeting was held on November 21 with representatives from ASU, Grand Canyon University, NAU, and the UofA, to further strengthen the alliance of universities and their respective programs, and increase awareness of inclusive PSE opportunities for students with I/DD.

Council members and staff are meeting with transition specialists and special education teachers, and sharing information on the Council, and our resources specifically created to increase awareness of PSE, transition, Graduation Targets, Apprenticeships, Career & Technical Education, ABLE accounts, and employment. We are also sharing policy briefs on Dual Enrollment, College-Based Transition Services, Project SEARCH, and Think College. We attended a Resource & Transition Fair at Tucson Unified School District and have been invited to attend a Career Expo and Chandler Unified School District's Build 4 Tomorrow.

Martin Appel, District Transition/TSW Coordinator, for Mesa Public Schools, wants to meet with the Sonoran Center for Excellence in Disabilities about possibly starting Project SEARCH in Mesa Public Schools and wants to know how to get the process started. Mike Leyva is

facilitating a meeting with Martin and Jacy Farkas to start the conversation. Project SEARCH is a unique business-led, one-year employment preparation program that takes place at the workplace. There are two programs – one for high school students transitioning into the workforce, and one for adults. It creates an opportunity for career-exploration through various hands-on training in a variety of departments. Participants acquire competitive, transferable, and marketable job skills. 344 Interns have graduated from Project SEARCH in Arizona, and 71% of Arizona Project SEARCH graduates obtained competitive integrated employment in 2019. I hope we can make this happen.

Council staff plan to create new Pathways to the Future resources which complement the six that were created last year. In addition to the others, *Preparing for College and Work for Refugees with Disabilities* will be shared with educators, transition specialists, support coordinators, and others to help individuals and families with transition and future planning.

Melissa thanked the Meaningful Careers committee for supporting these and many more activities during the past year and will coordinate with Michael Leyva to schedule the next committee meeting.

4. Behavioral Health & I/DD:

Jason Snead stated the Behavioral Health and I/DD committee released a crisis report over two years ago. Some core members of the committee have been meeting with state agencies, as well as managed-care organizations throughout the state to improve services to Arizonans with disabilities. The core group now believes that it is time to release a second report detailing the work that has been accomplished and explaining the work that still needs to be done. The core group will start meeting once a month in December to draft the report.

Some of the members of the core group were involved in the creation of the “*Stuck in the System: Searching for Better Criminal Justice Interactions for People with Disabilities*” report. A Criminal Justice roundtable was held at the Flinn Foundation in Phoenix on November 13, with more than 30 people from the community in attendance.

5. Work Plan:

Kathy Levandowsky stated the Committee met on November 1, 2024, and it was already mentioned in Jon’s Executive Report to the Council. Kathy did not add anything further to what has been stated and that the committee will meet in January 2025.

G. Staff & Grantee Presentations:

ADDPC 2024 Community Survey – Sarah Ruf presented on the community survey that was released in summer 2024 to gauge the public’s understanding of the Council and how they perceive the Council’s impact. Ninety-one individuals responded to the survey. Sarah highlighted the following themes:

- 81% are familiar with the ADDPC; 19% are not.
- 40% consider themselves to be a self-advocate; 60% are not.
- The ADDPC received a 3.3 out of 5 stars for the question, “In your opinion, how well does the ADDPC serve Arizona?”. Five individuals said not all, 11 individuals said excellent, and 12 individuals said just okay.
- Among the areas that were important to the individuals that responded, caregiver support, housing and employment were top of mind.
- They said there is room for improvement for the ADDPC
- The ADDPC must develop new relationships and partners to accomplish goals

- The ADDPC needs to leverage technology differently to reach audiences
- The grants program is not used to its full potential, with most of the survey takers not aware the ADDPC offers grants.
- In response to what the ADDPC should focus on in the next five years: Rural issues, Access, Social and Fun activities, Healthcare and Housing, Employment, Advocacy Training and DDD Providers.
- The respondents stated that the biggest challenges were Employment/VR; Being included in my community; Making friends and having fun; Finding services that respond to my unique needs and Healthcare services (mental, physical, dental, and other).
- 53% of the respondents did not know the ADDPC offers grants; 46% said yes, they were aware.
- In response to the question, "How easy was it for you to apply for an ADDPC grant?" the rating out of five was 2.5. Only 13 respondents answered this question.
- Of those that responded, the general feeling is that the process is cumbersome and confusing, the application is outdated and that the application itself is exclusionary, for example that match is required for all grants no matter the size of the award.
- The key takeaway: There is room for improvement.

Supported Decision-Making – Mellanie Mills, the Executive Director for The Arc of Arizona and Sey In, Staff Attorney for Disability Rights Arizona, joined together in providing an update on the Supported Decision-Making (SDM) grant funded by the ADDPC. They discussed why SDM is important as an alternative to guardianship, and emphasized the individual has much more say to determine their team that will support them in certain areas, but the ultimate decisions are left with the individual.

SDM is important because it empowers personal choice, builds confidence and independence, enhances quality of life, respects the rights and dignity of the individual, encourages growth in self-advocacy, strengthens social connections, and reduces over-dependence on guardianship.

As funded by the Council, Melanie and Sey have developed SDM training materials and resources to assist families and to educate a broad range of stakeholders. They conduct trainings virtually and in person throughout Arizona; materials are in plain language, Spanish and accessible; they use multiple advertising strategies to reach more individuals that live in rural communities; and they update their presentation materials for key audiences, such as the legal system or medical professionals.

Since July 2023, over 1,800 individuals have been trained on SDM throughout Arizona. Fourteen trainings have been done in person, and 23 virtual trainings have been completed. Surveys are collected after each training for both Melanie and Sey to review what areas need to be improved or changed. Both continue to update SDM materials, as needed, with input from the advisory committee and any new SDM legislation.

Melanie and Sey stated they continue to engage with DDD, APS, Mercy Care, UnitedHealthcare, Raising Special Kids, Care 4 the Caregivers, First Place, The Arc's local chapters, school districts and many more. They are in the process of creating specific presentations to empower others to train on all support options.

Arizona Self-Advocacy Coalition & Leadership Project – Ryan Barry, from The Arc of Tempe, and Melanie Mills gave an overview of the grant funded Arizona Achieve Self-

Advocacy and Leadership project, funded by the Council. Ryan is the Project Director for The Arc of Tempe. Ryan gave an overview of Arizona Achieve's purpose, "To establish and grow a statewide coalition of self-advocates who work together and learn leadership development, speaking skills, peer-to-peer mentoring, partnership with local self-advocacy groups around Arizona, and participation with community groups."

Arizona Achieve focuses on four tiers of advocacy:

- Self-Advocacy is speaking up for one's needs, preferences, and rights; and restores individual agency.
- Peer-Advocacy is encouraging individuals to share their stories and grow confidence
- Group-Advocacy is taking collective acting as a group to advocate for shared needs and rights.
- Systems-Advocacy is advocating for changes to policies, laws, or systems to benefit the disability population, spreads disability awareness, and creates long-term change.

Prior to funding The Arc of Arizona/The Arc of Tempe for the self-advocacy grant, there were only 20 self-advocates as part of the statewide coalition of self-advocates and they mostly were in Maricopa, Pima, Yuma and Coconino counties. With the grant awarded to The Arc of Arizona/The Arc of Tempe, Ryan and his team have taken a different approach to building a coalition of self-advocates and different outreach strategies to connect with more individuals. This has resulted in 47 self-advocates from 10 Arizona counties now participating in some part of Arizona Achieve.

To date, Arizona Achieve has hosted 15 coalition meetings; formed a peer-mentoring program; designed a website with 6,000 views; published multiple videos to its YouTube Channel; conducted 8 in-person workshops for self-advocates; created a 248-page leadership curriculum; met with state and national lawmakers; and partnered with the Protection & Advocacy agencies and U.S. Attorney's Office; and created a video on the Navajo Nation about the lack of transportation for individuals with I/DD and their families.

Future areas that Ryan said they will focus on include adapting the leadership curriculum to videos; empowering members to advocate for and introduce public transit legislation; building a multi-issue, cross-community coalition; improving minority representation; and streamlining legislative and policy change.

Ryan also stated that they continue to address challenges with Arizona Achieve and will be working on each area, such as balancing advocacy across multiple issues; engaging rural communities continually; addressing minority underrepresentation; navigating inter-organizational dynamics; maintaining membership participation; and operating without a community presence.

H. Announcements:

None.

I. Call to the Public:

None.

J. Adjourn:

Chairperson Melissa Van Hook adjourned the meeting at 12:27 PM.

Dated this 26th day of November 2024
Arizona Developmental Disabilities Planning Council

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