



FULL COUNCIL MEETING

DRAFT MINUTES

Friday, April 21, 2023

10:00 AM – 12:00 PM

3839 North Third Street, Suite 306

Phoenix, Arizona 85012

Pursuant to A.R.S. § 38-431.01 (G), the Arizona Developmental Disabilities Planning Council and its standing and ad-hoc committees may obtain public comment if it so desires. A formal call to the public will take place at the end of the meeting. Members of the Board may not discuss items that are not specifically identified on the agenda. The meeting was conducted by teleconference.

Council Members Present

Melissa Van Hook, Chair
Monica Cooper
Kin Chung-Counts
Vanessa Felix
Erik Jensen
Kathy Levandowsky

Kristen Mackey
Gabriela Orozco
James Rivera
Vijette Saari
Mary Slaughter
Sophie Stern
Mateo TreeTop

Council Members Absent

J.J. Rico, Vice Chair
Meghan Cox
Bianca Demara
Benjamin Kauffman
Kristina Lopez
Janna Murrell
Wendy Parent-Johnson
Kelly Roberts
Janet Vilorio

Council Staff

Jon Meyers, Executive Director
Marcella Crane, Contracts Manager
Michael Leyva, Contracts/Grants Coordinator
Lani St. Cyr, Fiscal Manager
Jason Snead, Research & Communications Specialist

Members of the Public/Guests

Maureen Casey, Director of Public Policy and Applied Research at First Place Global Leadership Institute
Lionel Delgado, public member, Yavapai County

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 10:14 AM. Introduction of Council members and roll call completed.

B. Minutes from January 20, 2023, Meeting

Chairperson Melissa Van Hook reviewed the January 20th 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 January 20, 2023, minutes. Kathy Levandowsky made the motion, seconded by Monica Cooper. 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 received the full allotment for FY 2021, in the amount of \$1,500,930 and has met the original September 2022 obligation deadline. However, ACL has granted a one-year no cost extension for FY 2021 funds making the new obligation and project period through September 30, 2023, allowing an additional year for the work to be completed. The Council will have until December 31, 2023, to liquidate FY21 funds. There is approximately \$8,670 to be liquidated.

The Council has received the full allotment for FY 2022 in the amount of \$1,500,930, which is the amount previously estimated. This is level funding to FY 2021 excluding the Puerto Rico reallocation. The obligation and project periods are through September 30, 2023, with the liquidation of funds through September 30, 2024. There have been discussions regarding a no-cost extension for these funds as well, but nothing official has gone through yet. The Council has fully obligated these funds and there is approximately \$656,846 remaining to be liquidated.

The Council has also received the full allotment of FY23 funding in the amount of \$1,500,930, which is level funding with the prior two fiscal years. The obligation and project period are through September 30, 2024, with the liquidation of funds through September 2025. There is approximately \$709,500 to obligate, which staff would like to do before this September so the work can be completed in the second year of funding to meet the period of performance requirement.

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. These funds are being tracked and reported separately. ACL has also granted a one-year no cost extension for using these funds, which the staff submitted a letter requesting. The funds must now be obligated, and work completed by September 30, 2023.
- To date the Council has spent \$43,007 and has encumbered \$40,355 through September 30, 2023. The remaining balance of the award will be used in partnership with NAU/IHD on a project to better understand the lived experiences of people with disabilities throughout the pandemic including barriers to health services such as awareness of and access to the Covid-19 vaccine.

Expanding the Public Health Workforce within the Disability Network

- The Council has received an additional award in the amount of \$95,319 to expand the Public Health Workforce within the Disability Network. The funds will also be tracked and reported separately. The

obligation and project period are through September 30, 2024.

- Currently staff are working to get a contract in place for these funds.

Council Funded Projects

The following contract changes were highlighted:

- The Spina Bifida Association of Arizona will no longer be conducting its conference.
- The Opportunity Tree Sexual Education Conference has been granted a 3-month no-cost extension through September 30, 2023.
- The Sonoran UCEDD Online Learning Modules have also been granted a 3-month no-cost extension through September 30, 2023.

Arizona Developmental Disabilities Planning Council Budget Recommendation

- This sheet now reflects the projects outlined in the FY 2023 Workplan. There may be some adjustments made to this document as we continue to review the workplans and what may be shifted for FY 2024.
- There may be additional FY 2023 funding to obligate, so the Workplan Committee is currently discussing ideas for any additional funds that may need to be obligated.

D. Executive Director Report:

Jon Meyers reported on the following agenda items -

- Council vacancies/renewals/appointments:

Jon stated that he has been in communication with Governor Hobbs's administration, the Governor's Office of Boards and Commissions, to ensure the remaining vacancies are filled. We're awaiting official notification to fill the DES/DAAS position and the reappointment of another Council member. Jon is hopeful the Council roster will be completed soon to share. Jon also shared information will be forthcoming for those Council members whose reappointments will be considered in September 2023.

Sophie Stern stated that she is part of Detour Company Theatre. Jon stated that Sophie was introduced on the floor of the Arizona House of Representatives, by Representative Jennifer Longdon, as the newest member of the Arizona Developmental Disabilities Planning Council.

- Programmatic Progress Reports (PPR) 2022 Update:

Jon stated the FFY 2022 PPR was completed on December 30, 2022, and submitted through the Verity system to the Administration on Community Living (ACL). Jon stated that ACL is in the process of reviewing the reports and as of now, Arizona is not one of the states that needs to clarify any part of the PPR.

- FFY 2023 Work Plan Update:

Jon and staff recently met to review 6-months of work on the FFY 23 work plan. The FFY 23 work plan must be concluded by September 30, 2023. Staff meets quarterly to provide updates for each of the activities under the five goals. Staff also met with the Work Plan Review Committee to discuss what has been accomplished to date and seek their input on the development of the FFY 24 and 25 work plan drafts. Council members will have a chance to offer their input to both drafts at the next full Council meeting, scheduled in June. Kathy will provide additional information in her committee report.

- Covid-19 Vaccine Hesitancy and Public Health Workforce Development special funding updates:
Jon stated that he submitted the first report to ACL on March 31 regarding the portion of the Vaccine Hesitancy funds that was used by Michele Thorne and Michelle Jacquez, to undertake a study on parents and caregivers, people with I/DD and the I/DD community on their attitudes towards Covid vaccines and hesitancy concerns. The remaining \$45k funds are awarded to NAU/IHD for additional work through a formal contract. NAU/IHD will look at conducting a survey to gather additional input from individuals with disabilities in Northern Arizona, including tribal communities. This work will supplement what NAU/IHD is already doing with their direct funding from the CDC. That information will then lead to a better understanding of what the medical community and its partners can do to address vaccine hesitancy and alternative ways to communicate messages about the importance of vaccines. NAU will have until September 30, 2023, to complete the work.

For the Public Workforce Force funds, Jon stated he is working with a group of collaborators to finalize a scope of work and budget for \$95,319 that will be used to support wages and benefits for public health professionals (directly or through contract) as well as the costs associated for equipment, training and supplies. The Council will partner with the University of Arizona-Sonoran UCED and the Western Arizona Health Education Center (WAHEC). Currently, a draft scope of work has been developed on addressing needs of the aging I/DD population, including a budget and soon a contract will be in place. There have been delays due to finalizing the budgets, but Jon stated a contract should be finalized in the coming weeks.

- Legislative/Policy Update – 2023 Session:
Senate Bill 1411, as introduced by Senator Justine Wadsack, originally stated that anyone receiving services from DDD would automatically and immediately on their 18th birthday fall under the guardianship of their parents, unless the parents notify DES that they didn't want to become their child's guardian on their 18th birthday. The bill in its original language is very concerning to the disability community, with many objecting to it.

Jon organized a letter opposing this bill, and he and others were able to meet with the sponsor to convey their concerns. She introduced an amendment in the Senate, however, unfortunately the amendment was only marginally better than the original language and still wasn't something that the disability advocacy community could live with. But she stated a willingness to work with advocates on a floor amendment in the House once it was transmitted from the Senate. The bill as amended passed and moved to the House.

At this time, the bill has stalled in the House and it might be too late for it to be assigned to a committee for a hearing. We're watching striker bills to see if it is resurrected onto another bill, but currently, it does not appear there is any movement on SB 1411. Jon stated that this will give the disability group a chance to meet with Senator Wadsack and continue educating her on why this bill would do more harm than good.

Council members Kristen Mackey, Kathy Levandowsky, Kin Counts and Melissa Van Hook all made comments and/or asked questions about the intent of the legislation. Some Council members wanted to know the Senator's background and if other parents were there to discuss their own experiences and opposition to the proposed legislation.

Another important point stated by Kathy is the knowledge of the support coordinators in this discussion with families. Jon stated it is very important that DDD support coordinators not provide legal advice but educational materials so that they understand the choices that are available to them. Jon has

communicated with DDD on the need to develop materials and they are open to the Council's support.

Kin asked how the court petition for guardianship can be easier for families, as they express frustration on how difficult and long it takes. Jon stated that Senator Kavanagh introduced two bills this year related to that very topic of improving the guardianship system and making it more transparent, accessible, and easier to navigate for individuals who need to petition the court for guardianship. Staff is tracking both bills. Senate Bill 1038 has passed both the Senate and House and is now back in the Senate to take up the House amendments. The primary intent of this bill is to create a Probate Advisory Council that would undertake the work.

SB 1710 addresses oversight of the Arizona State Hospital (ASH), which is the state's mental hospital. The bill moves administrative oversight from the Department of Health Services, where it currently resides, and puts it under an independent governance committee. There are pros and cons on this bill. ASH has been notorious for quite a few years for a variety of reasons, and in large part, has to do with issues about quality of care for all the residents, especially when it comes to the I/DD population, and has been noted for its lack of transparency, lack of information, and lack of proper treatment.

Jon stated that the main concern with the proposed legislation is that the bill does nothing to improve AHS, it doesn't specify anything to improve conditions for people with I/DD. It simply moves the oversight from one agency to a governing body and it is not clear what their role is either. The Council, along with NAMI, ACLU and the Arizona Peer and Family Coalition signed a letter opposing SB 1710.

The bill has passed the Senate and it may pass the House; the question becomes if Governor Hobbs will sign the bill or not. There are some indications that she will veto it, but we don't know for sure. Jon also noted that he spoke to Will Humble, the previous director for the AZ Department of Health Services and a past Council Chair, to get his opinion. Will is supportive of the bill, and his reasons make a lot of sense, but there are a number of unknowns regarding the I/DD community that are still troubling to Jon and to others who've been part of these conversations.

Jon expressed optimism that whether the Governor signs the bill or vetoes it, disability advocates will have a chance to continue working with those who support the bill and particularly with the new governance body, or if it gets reintroduced next year after it is vetoed, there will be a chance to contribute new rules that will improve conditions for people with I/DD who are admitted to ASH.

On a final note, Jon stated that related to this bill is the report on Crisis in the Behavioral Health system the Council issued last year. There has been a lot of good work done in this area, and we certainly do not want to take any steps that negatively impact the disability community.

Senator Shope introduced an appropriation bill of \$60M for DDD services. In contrast, Governor Hobbs's budget proposal did not include any new money for the DD service system for fiscal year 2024, Senator Shope's bill passed the Senate, however, it failed in the House Appropriations committee. At this time, we're waiting to find out if the Governor's final budget will have any new monies for the DD service system.

The Governor's rationale for not putting any new money into the bill was there's already a lot of money from the American Rescue Plan Act (ARPA). These funds will expire in 2024. So the discussion

for the future has to center on adequately funding the DD service system since the rate of inflation has really been a barrier to the provider community, ultimately impacting families and the care that persons with I/DD need.

Jon gave an update regarding President Biden's recently signed Executive Order related to improving care availability and accessibility of caregiving for people with disabilities, childcare, disability services for veterans, and a variety of other care-related purposes. The E.O. initially generated a lot of enthusiasm, as shown by the endorsements on the White House website. Jon admitted he takes a slightly contrarian view about that because virtually every cabinet agency will have to find new ways to improve services or expand services without a single financial allocation involved in the Executive Order. Without money, it's going to be very difficult for our federal agencies to make a lot of impact on the issues facing families and the cost to have adequate home care for vulnerable populations.

Jon also stated he recently did an interview with KJZZ on the effects of this Executive Order. He stated it's really important to get these issues out there but we all have to temper our expectations and recognize that without congressional funding and action to put more money into the system, it's just going to be virtually impossible for a lot to happen. Jon is hopeful that the Executive Order can motivate Congress to act.

- Upcoming NACDD/ITACC Events:
The 2023 OIDD Training and Technical Assistance Institute is online and scheduled over several days, May 10-11 and May 16-17. Registration is free and is now available if anyone is interested in attending.

The NACDD Annual Conference is scheduled for July 26-28, 2023, in Orlando, Florida. Registration opens on May 1. Council members who are interested in attending should let Jon know.

E. Committee/Workgroup Reports:

1. Grants Update:
Marcella Crane stated that two grant solicitations are under review by an outside evaluation committee and the final recommendations will be on the Full Council agenda for June. Two other grant solicitations closed on April 20th and those will soon be evaluated, as well, during the summer and the Council will have a chance to consider those applications in September. Overall, it has been a very busy spring and Marcy thanked the staff for their assistance.
2. System Access & Navigation:
Mary Slaughter provided the update on behalf of the committee. The work plan consists of three areas to address: Helping families, and individuals with I/DD to better access and navigate services and have better information to do that. The concentration is on early childhood and diagnosis in early childhood. The second focus is on youth transition during their time in school. And the last focus will be to address the elder I/DD population and the availability of resources for that population. The committee discussed how to put all this information together so it is helpful and available in a format that will be used, so that it's not duplicative of information already available. Mary stated progress is being made to address this.

3. Meaningful Careers:

Melissa Van Hook provided the update on behalf of the committee. The Institute for Community Inclusion (ICI) is conducting research on Arizona's Vocational Rehabilitation Policies and Programs. Beginning in January 2023, ICI staff began outreach to stakeholder groups recommended by ADDPC and Vocational Rehabilitation. So far, they have conducted interviews with 18 people connected to VR: including supervisors, counselors, program manager, Pre-ETS providers, attorneys, and directors. ICI has also conducted 7 interviews with people connected to the Department of Education and local school systems, including school district transition program directors, transition coordinators, and a family member.

The ICI team met with the Meaningful Careers Committee on March 28th to discuss stakeholder interview findings, as well as to request assistance with outreach to students and families. The findings to date were presented to the Committee as Arizona's strengths and areas for improvement. The Committee agreed with the initial findings, including that there were opportunities at the local level to expand and initiate innovative practices; that staff training and retention is an issue impacting the quality of services; and that communication must be improved within and between departments in Arizona who have shared responsibility for transition from school to work (DDD, DOE, and VR). When the Committee was asked about the best way to support change in Arizona's VR system, it was suggested that small steps would be taken more favorably as would direct guidance about the responsibilities of each department. And bringing more families to the table to help departments move away from pushing alternatives to employment was also suggested as was potentially tying transition to the ADDPC's upcoming 5-year plan.

To increase participation of youth and families who have received transition services through VR, ADDPC granted approval to offer a \$25 Amazon gift card per household for every individual and family member interview. The intent is to honor the time that individuals and families will allocate to participating in the interview and hopefully generate more engagement from those stakeholders. Jon and Mike compiled a list of organizations and individuals to help ICI recruit individuals and families for interviews.

The Center for the Future of Arizona is working full steam ahead on the Communities at the Center Project. They have been meeting with groups and organizations to inform and prompt dialogue around issues impacting the transition of young people with disabilities into postsecondary education and career success, as well as engaging cross-sector leaders to understand the challenges in and opportunities for advancing equitable access, and surfacing opportunities for action. Melissa emphasized we want to include representation from early childhood and we have reached out to Arizona Early Intervention Program (AzEIP) to request staff participation. She thanked Kathy Levandowsky for facilitating an introduction for Mike. He has reached out to Annie Converse and is waiting for her recommendation. If any Council member would like to assist with this important project, please contact Melissa.

Melissa expressed her particular pleasure about one listening session held on February 27, with Grupo de Apoyo para Ninos Especiales (GANE). There were 20 participants engaged in interactive discussion using the Arizona Town Hall model of consensus and developed priorities and recommended actions. The feedback from the GANE support group is excellent; it mirrors her own experience and most of all the parents she knows with children with disabilities. She shared her gratitude with fellow Council member Gabby Orozco for her help in organizing the session.

Melissa also commended the Center for the Future of Arizona for the Statement on Equity they prepared while conducting a listening session with the East Valley Consortium. She recalled a quote regarding education from Ellen Notbohm, a parent of a child with ASD and a consultant on ASD: " 'Fair' does not mean everything is equal. 'Fair' is when everyone gets what they need." Melissa agreed that there needs to be a lot more discussion in the area of equity.

On April 11th, State Senator Steve Kaiser presented Senate Concurrent Resolution 1012 supporting Employment First and greater employment opportunities for persons with disabilities to his Senate colleagues. Melissa stated this might be one of the most important pieces of business the Legislature attends to this session. What it did was affirm that every person, regardless of ability, should have the right to pursue meaningful work that is essential to improving their quality of life, increase their community participation and empower them to make their own choices in life.

The resolution is an important step for lawmakers to better understand the very real challenges facing individuals with disabilities in their pursuit of meaningful work, our labor force constraints, and the needs of employers who might want to tap a new workforce, but who don't know where to start or what questions to ask.

4. Behavioral Health & I/DD:

Jason Snead provided the update. Flyers and reporting forms were distributed in Spanish and English regarding the removal of communication devices in residential facilities, behavioral facilities, and schools. This distribution was a result of the crisis report that the Council and several other disability organizations took part in over a year ago. Since then, the behavioral health core team has been meeting periodically to continue to try to address issues around the crisis system in Arizona. There has been very little feedback from the flyers and the reporting form, but we have received some emails and have addressed those issues. We have also seen some policies created by the Arizona Health Care Cost Containment System (AHCCCS). However, even though policies have been created there has been no consistent training around these policies, therefore these policies have little effect on the crisis system itself. To try to address this concern the core team plans to put together a survey asking individuals about their overall experience with crisis in Arizona and the effort to gather information to bring to key policymakers.

5. Work Plan Review:

Kathy Levandowsky provided the update. Kathy stated that the committee's first meeting was to review the entire 2023 work plan, each goal and activity, and to understand how the budgets are developed and tracked. It was very helpful to hear this information from staff. The second meeting was to address what should be carried over and/or new for Self-Determination and Meaningful Careers, however the committee had such good discussion on the Self-Determination Goal, there was no time to address the Employment goal.

The committee realized that they need to meet more often to get through each of the five goals so that there is a draft of the FFY 2024 and 2025 work plans ready in June for discussion and vote. Kathy thanked all the committee members (Melissa, Bianca, Monica, and Mary) and the staff for their support and guidance.

F. Community Presentation:

Maureen Casey, Director of Public Policy and Applied Research for First Place Global Leadership Institute, provided a presentation on housing for adults with autism and intellectual and developmental Disabilities (A/I/DD), and other neuro-diversities, "Making the Invisible Visible." Maureen began her

presentation by giving an overview of First Place located in Phoenix. First Place offers the autism community, housing/apartments with supportive care (n=63 apartments), a transition academy for 16 students at a time (2023 class will soon graduate - it is clinically based for participants and students), and a global leadership institute for support providers, professionals, researchers, and policy leaders, which focuses on marketplace research and analysis.

The need for this research was born out of the knowledge that adults with A/I/DD face a critical shortage of housing options and access to supports they need to thrive. To drive the future planning, funding, and significant advancements in public policy, the First Place Global Leadership Institute Center for Real Estate & Community Development launched a comprehensive housing market analysis of needs and preferences in Greater Phoenix.

The key theme from this presentation is that the research shows there is a need for affordable housing for adults with A/I/DD and policy makers should ensure they can offer affordable and cognitively accessible, mixed-housing options with greater access to services when individuals with A/I/DD are deciding where to live. There needs to be a national housing action plan that can be in place to support individuals with A/I/DD and those with other neurodiversities.

A PowerPoint slide and back-up materials were made available for the Council members. Some key points in Maureen's presentation are the following:

- At least 159,000 individuals in AZ have an I/DD.
- 77% live with family, yet for many their family is aging.
- 27% live with a caregiver over the age of 60 that also needs housing and support in place to live independently.
- In her approach to a market analysis for data-driven solutions, Maureen addressed 4 areas where survey data was collected: Educate neurodiverse community; Assess preferences and support needs; Approach housing industry with consumer data; and Increase housing stock that meets local needs.
- A person-centered approach includes housing, meaningful activities, support services, employment, natural supports, volunteering, and future stability.
- AZ statistics on residential options show that to afford a 1-bedroom apartment, an individual needs to work 65 hours/week at minimum wage; and to afford a 2-bedroom rental home, an individual needs to work 79 hours/week at minimum wage.
- There are only 601 housing vouchers targeting anyone with any type of disability in the greater Phoenix area. There are approximately 59,000 people that need vouchers.
- Survey responses show that 43% receive SSI; 40% receive Medicaid; 27% receive SSDI; 16% receive SNAP; and 3% receive a Housing Choice Voucher.
- A Greater Phoenix Area Housing Strategies by City/Locality overview shows the main cities in Maricopa County (Phoenix, Mesa, Glendale, Scottsdale, Tempe and Surprise) have a waiting list for affordable housing and most cities do not identify people with A/I/DD specifically as a need. To receive a spot on a waiting list is on a first-come, first-served basis.
- Recommendations from a group of community and disability leaders were used to come up with this list to develop a housing and community roadmap. It includes closing the data gaps; increasing homeownership, rental subsidies, and development of Neuro-inclusive Mixed-Use and Planned Communities; exploring innovations in long term services through ALTCS-DDD; and addressing local community development.
- An overview of policy steps toward creating affordable and supportive housing for adults with A/I/DD was provided that addressed Functional Challenges, Systemic Challenges and HOPAIDD, a model program to create consumer-based housing opportunities and supportive amenities for

neurodiverse adults. HOPAIDD can be replicated from the model program HOPWA or Housing Opportunities for Persons with AIDS. This housing program is congressionally funded and is meant for those individuals diagnosed with AIDS and who have low income. HOPAIDD can be modeled similarly.

- Functional challenges mean how limited accommodations address physical, mental or cognitive challenges that interfere with daily living.
- Systemic challenges point to the fact that there is no single source of funding for housing, healthcare and supportive services. Federal/State dollars are siloed by various agencies and too complex for individuals with A/I/DD and families to navigate for assistance.
- The research affirms that the common barriers to obtaining affordable housing for persons with A/I/DD are discrimination, limited information, complex social system, and high demand for vouchers. The additional barriers add another layer to overcome: Economic challenges, social challenges, and executive functioning challenges.

Council members appreciated the presentation and asked questions and/or made comments. Kin asked what the average wait time is for those waiting for a housing voucher. Maureen will check.

Kathy asked why the wait list is closed by the city/locality? Maureen stated it is because it depends on the funding by the agency. To get more applicants, they put people on the wait lists hoping they get more funding.

Melissa stated the presentation and research report was excellent and thanked Maureen. All of this information is posted on the Council website under this meeting tab. Maureen's information can also be found at www.FirstPlace.org.

G. Announcements:

None.

H. Call to the Public:

Mr. Lionel Delgado, a public member, made the following comments.

1. Regarding SB 1411, Guardianship, Mr. Delgado wanted to know if it impacted those families whose child is not under DDD? The answer is no. Only for those people with I/DD that are qualified and receive services under DDD.
2. He wanted to know how many DDD homes have installed cameras? Jon did not know the answer.
3. A camp in Williams doesn't include people with I/DD with behavioral health issues. He is requesting that an advocacy organization such as ADDPC or ACDL address this as a violation of law.
4. Can the Bylaws be amended to allow public comment after each agenda item? No, not per Open Meeting Law.

Melissa appreciated the questions and feedback from Mr. Delgado; staff will research his concerns.

I. Adjourn:

Chairperson Melissa Van Hook adjourned the meeting at 12:18 PM