



SYSTEM ACCESS AND NAVIGATION COMMITTEE

Meeting Minutes

March 12, 2024

1:00 pm-2:00 pm

Arizona Developmental Disabilities Planning Council
3839 North 3rd Street, Suite 306, Phoenix, Arizona 85012

Meeting held by teleconference

A committee meeting of the Arizona Developmental Disabilities Planning Council (ADDPC) was convened via Google Meet on March 12, 2024, notice having been duly given. Present were the following members of the System Access and Navigation Committee, guests, and staff.

Committee Members Present

Janna Murrell, Chair
Katharine Levandowsky
Vijette Saari
Mary Slaughter

Staff and Guests

Jon Meyers, Executive Director
Marcella Crane, Contracts Manager
Sarah Ruf

Amber Owens, Intern
Barbara Picone, DES
Yumi Shirai, UA/Sonoran UCEDD

Committee Members Absent

Bianca Demara
Kin Chung-Counts
Kelly Roberts

A. Welcome & Introductions

Chairperson Janna Murrell welcomed everyone to the Arizona Developmental Disabilities Planning Council (ADDPC or Council) System Access and Navigation Committee meeting. The meeting was called to order at 1:03 pm.

B. Review of December 12, 2023, Meeting Minutes

Janna Murrell asked members for a motion to accept the draft Minutes of the December 12, 2023, committee meeting. Mary Slaughter moved to approve the minutes; Kathy Levandowsky seconded the motion. Motion carried without objection.

C. Committee Purpose, Goals, Vision

To begin every meeting, Janna wants to ensure that the committee members know what the purpose is of the System Access and Navigation Committee. Janna read the Goal and Objectives to reorient everyone to the tasks at hand.

D. Update on Activities

Committee staffing change:

Jon welcomed Sarah Ruf as the ADDPC's Council's Director of Communications. Sarah will be the lead staff person on the Systems Access & Navigation Committee. The Committee members welcomed Sarah and are excited to work with her on implementing the activities under the goal.

Getting Started Guide:

Amber Owens provided an update on the Getting Started Guide.

She made changes to the layout so that it is easier to use. The Navigation Page has four areas for the user to click on that will take them to the next level of what information and resources they are looking for. The four areas are Birth to Age 5 Resources; K-12 Resources; Transition to Adulthood Resources, and Transition to Elderhood Resources.

Janna thanked Amber for listening to the committee and taking their feedback to change the layout of how the information is presented.

Mary mentioned the guide no longer seems overwhelming to look at and for families to use. Mary approved and thanked Amber.

Kathy recognizes the work that went into redoing the layout.

Amber said she needs to incorporate the guide into the ADDPC website. Amber believes it is ready to share and receive feedback from users.

Janna made a recommendation to send the current guide as a pilot to a group of stakeholders and receive their feedback.

Kathy agreed with the recommendation and for the user in the pilot to use a survey. She asked Janna if the parents she works with at Raising Special Kids can try this out. Janna said yes.

Janna also wanted to ensure that self-advocates can use this and provide feedback.

She then asked the ADDPC how it will be incorporated onto the ADDPC website.

Sarah stated that the Council track constituent calls and thinks this may be a good idea to have those folks try this out and provide feedback. In terms of how to receive

feedback is through a Google Form or through SurveyMonkey or another type. Sarah is open to ideas and strongly believes that end-user feedback is important.

Amber does not have any idea how many users should try this. Amber created a feedback survey that is already embedded in the tool. She wanted to know if a different survey needs to be created for the test pilot.

Janna and Kathy said no. The survey has been created and can be used. Kathy wants to make sure that folks of different ages and needs try the Getting Started Guide and provide feedback to the committee.

Sarah stated she is still waiting for access to the ADDPC website. She liked that it is a slideshow that can be embedded with the Council's website. She asked if Amber could create a blurb of keywords that can be picked up on a Google search and lead people to the ADDPC, where this will pop up.

Janna said that the survey has been updated in previous meetings, and she feels it looks good and is ready. The survey pops up for the user, and Janna does not feel any more changes are needed.

Janna wanted to ensure that several groups will be targeted for the pilot to review the Getting Started Guide, including parents at Raising Special Kids and previous constituent callers to the ADDPC. Mary suggested asking elder groups and asked Barb for contacts. Kathy provided the information from the Intertribal Council of Arizona and will follow up with a contact.

Janna described the next steps for Amber and Sarah, specifically writing a blurb and compiling a list of who can receive this guide to get feedback. Janna wanted to send this out sooner rather than later and have the results ready at the next Systems Access meeting. Janna thanked Amber for all her work and effort.

Public Health Workforce Development Project:

Jon stated that the Regional Center for Border Health submitted two draft reports for review by the ADDPC. Jon is in the process of providing feedback to the contractor and once the final reports are completed, Jon will share them with the committee members. This was part of the COVID-19 funding, with Sonoran UCEDD as the contractor.

The findings were broken into six key areas or themes:

- Accessibility and affordable healthcare – Persons with I/DD and their families stated accessibility and affordability with the healthcare in their community is either not available or not easy to access. The need for both will only grow as they age.
- Housing and food security – It was stated by focus groups that the cost of housing is high and there is a shortage of affordable housing. Both issues are important for families and caregivers, as they want to remain in their community where they feel safe.

- Inclusion and civic engagement - To ensure that persons with I/DD and their caregivers are involved in their communities regardless of their age. At any age, they shared it's important to not feel isolated but engaged. A concern is that as persons with I/DD age, their caregivers or families may limit their community engagement and keep them more indoors.
- Legal/Guardianship /Estate Planning and Advance Directives. - Many families are not aware of the legal process to have in place for their loved one once they are no longer alive or in a capacity to care for the family member with I/DD. Some stated the process is expensive. Other families said they are unsure where to begin or know what legal means will be needed.
- Transportation – Concerns were expressed that public transportation is not available, safe, and reliable in their community. This can lead to missed healthcare appointments, limited employment opportunities and community engagement activities.
- Education/Employment – Families and caregivers said they want their loved one to receive appropriate education and can gain meaningful employment. But many were frustrated with the school system and lack of transition services and information for their family members with I/DD. Caregivers expressed more concern on this last topic (education and employment) than the other.

The report has great information synthesized on each of these six themes, and there are powerful quotes from family members and caregivers on why these issues are important to them. Many expressed their fears and frustrations on these issues.

Mary stated these reports are important and is eager to read them. Mary said the summary that Jon provided matches point by point with what the aging community says they are concerned about. This can become the outline as their concerns are no different for the general aging population and there are solutions to these.

Jon agreed with Mary. He said this will support the Community of Practice and the work the committee will do, and this will prevent any additional research, as the data is current and is from the perspective of rural and un/underserved communities and Spanish speaking families.

Mary said to Amber that these themes could be used to organize resources for the Aging over 50 Guide; Amber agreed.

Yumi was glad to hear so a lot of good information and said the committee should highlight what is unique to both populations, for example working with the fiduciary groups to focus on what needs attention. Yumi also wanted to know what other states are doing to address the gaps for the aging population.

Jon said there are 16 other states working on the CoP. We will have an opportunity to learn from other states how they are approaching these challenges.

Janna said there is a huge benefit to sharing individual stories from family members since their voices are powerful and help to change policy.

Jon thanked the Regional Center for Border Health and their outreach efforts and the partners they involved. They were excited to work on this and were able to do many of these focus groups with Spanish-speaking families and in other communities outside of Yuma. There is a lot of rich information about how diverse the state is and how there is not a lot of equity in these rural and un/served communities.

E. National Community of Practice – Bridging Aging and Disability Networks

In the previous minutes, Jon provided the link for the committee to read more about this Community of Practice, or CoP (<https://nacdd.org/bridging-aging-and-disability>). States are invited to participate and NACDD is seeking participants to join a new cohort in Year 3 of the initiative.

The ADDPC's application was accepted by the Administration on Community Living, and there are now 17 states/groups doing this work. Jon attended a project facilitator call the previous week. Jon thanked Barbara Picone for selecting one of her staff to be on the workgroup.

Lots of other organizations are participating, including DRAZ, Sonoran UCEDD, DDD, Division of Aging, Pima Council on Aging, Tempe Arc, NAU/IHD, The Arc of AZ, Native Center, which is part of the Sonoran UCEDD, GANE (Spanish language support group by Council member Gabby Orozco) and we're still looking for more organizations from un/underserved communities and other aging entities to be involved.

Jon said the next step is to coordinate a meeting with all the partners involved and begin developing a state plan. Jon will also participate in monthly check-in calls. The Arizona CoP will also participate in calls with the other participating states every six months.

The CoP will have three years to implement the state plan (FFY 2024 – 2026) to develop specific outcomes, such as policy. The work does not end in 2026 but should continue as this is a very important issue to address.

Mary said the work is exciting and has other ideas of other groups who should be involved. She mentioned Hospice of the Valley since they have a person who specializes in hospice for people with I/DD. Also, Arizona State University has the Ollie Center—they have extensive ability to do this kind of community education. The Foundation for Senior Living in Phoenix also does extensive networking around the state.

Mary will send Jon contact information. Jon said that Erica McFadden had some leads on this topic, and he will be reaching out to her, as well.

Jon asked Barbara for the DDD perspective, she responded that she had not talked to Nicole Palomino about this. She loved to hear how Hospice can be involved.

Jon will be keeping the committee informed as work begins.

Janna said it was exciting to see things happening and thanked Jon.

F. Call to the Public

None offered.

G. Adjourn

Prior to ending the meeting, Janna scheduled the next meeting for June 18, 2024, at 1:00 pm. Sarah Ruf will send out a meeting invite.

Kathy Levandowsky motioned to adjourn the meeting. Mary Slaughter seconded the motion. The meeting adjourned at 2:05 pm.