

# SYSTEM ACCESS AND NAVIGATION COMMITTEE

Meeting Minutes
December 12, 2023
1:00 pm-2:00 pm
Arizona Developmental Disabilities Planning Council
3839 North 3<sup>rd</sup> 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 December 12, 2023, 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

#### **Staff and Guests**

Jon Meyers, Executive Director Marcella Crane, Contracts Manager Amber Owens, Intern Holly Hulen, NAU/IHD Barbara Picone, DES Yumi Shirai, UA/Sonoran UCEDD Bianca Demara Mary Slaughter

#### **Committee Members Absent**

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 1:02 pm.

### B. Review of October 24, 2023, Meeting Minutes

Janna Murrell asked members for a motion to accept the draft Minutes of the October 24, 2023, committee meeting. Vijette Saari moved to approve the minutes; Mary Slaughter seconded the motion. Motion carried without objection.

# C. Committee Purpose, Goals, Vision

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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

## Getting Started Guide

Amber Owens presented updates from the feedback she has received to date on the draft template and resources for the Getting Started Guide. From the last meeting, committee members provided Amber with additional information that she has added, inlcuding resource information on various agencies' Office of Individual and Family Affairs (OIFA).

She also noted that the ADDPC's intern, Emily Detwiler, continues to research resources to add for the Elderhood pages and that her assistance to the project is appreciated. Amber also discussed updates to the survey for site users and what questions are still missing but should be added.

Committee members feedback is summarized:

Mary wanted to review the weblink for the Resource Guide; Amber will email the link to everyone. Mary sent questions to Amber and said the Resource Guide looks good.

Jon suggested changing the word "caretaker" to "caregiver" in the second question.

Yumi asked if more questions could be added. Amber stated she worked on these with Mary and Emily and can add more questions. Yumi stated it would be helpful to include information from a focus group held in Tucson as part of the Public Health Workforce Development project. Jon will have information once the results of that project are reported.

Janna also provided feedback to Amber. She asked if information on Medicare/Medicaid should be added? Committee members agreed with Janna.

Kathy suggested changing "How I can find a good caretaker?" to "Where can I find a good caregiver?" Bianca said it can be phrased or added, "What qualities make a good caregiver?"

Next, Amber reviewed the user survey and the list of questions. The demographic information will be sent by Marcy after the meeting so that the Council can accurately report the data to ACL.

Amber received good input on the survey questions from everyone and will update the survey. Tribal information was discussed, and it was decided to leave that fillable for the person to voluntarily state what Native American Tribe they are affiliated with. Mary

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suggested to add Age categories in the Demographic section. She wanted to know the general age category of persons using the Resource Guide as well as the general age category of persons with disability that the resource material is for.

It was suggested that Area Agencies on Aging and Senior Companion program both do a presentation to the committee.

Amber will add all the feedback to the Resource Guide, update the Survey and continue to work on the elderhood resource site. Janna thanked Amber for all her work.

### Public Health Workforce Development Project

Jon stated that the project is ongoing and that 8-10 focus groups have taken place, approximately 61 individuals participated, including individuals with I/DD, family members/caregivers, and professionals. Two focus groups were done in Spanish, the remaining in English. As a reminder, the contract with the UA Sonoran UCEDD is in place until December 31, 2023, and the ADDPC will receive a final report that will include the data analyzed from all the participants in the focus groups and next steps. Jon will provide the report to the committee.

Some of the common themes from the focus groups show there is a lot of frustration related to the lack of services and supports for rural communities. There is concern about how to improve access to health care. Many of the participants stated the health care system doesn't live up to the promises it makes. Participants also stated that they are not made aware of the services or care they should receive after a diagnosis. Diagnosis of a disability comes too late for anything to be coordinated.

Families/caregivers expressed that they need development in certain skills to know how to care for a person that has I/DD and is aging. Many of them stated they are not equipped for that transition and how to appropriately care for this type of person.

Providers are struggling with how to provide high quality of life for persons with I/DD and for providing skill development. Retention of quality caregivers is also a huge concern.

# Discussion by Committee members:

Kathy: We need to work on this topic for the long term and she is looking forward to the final report.

Mary: Is also looking forward to reading the report and understanding what the needs are related to policy, to develop a strategic plan around the findings. Mary will reach out to other states.

Janna: Very helpful to hear this and how so many are interested in impacting the system. She stated that one thing RSK learns from focus groups and listening to the community is to follow up with the community with what the organization(s) did with their

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feedback. She suggested that the Council and the contractor need to circle back with those participants.

Bianca: Did a focus group in 2017 with the Regional Center for Border Health while working on her master's degree, and the community wanted to know what will change or come out of their feedback. She agreed with what Janna stated – to circle back to the community.

Jon: Agreed with everyone and will share this feedback to the contractor.

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

Jon provided the link for the committee to read more about this Community of Practice (<a href="https://nacdd.org/bridging-aging-and-disability">https://nacdd.org/bridging-aging-and-disability</a>). States are invited to participate and NACDD is seeking participants to join a new cohort in Year 3 of the initiative. This involves a coalition of groups and Jon will be following up with DES and others to see if there is any interest in Arizona to apply.

Mary said this is great news and it might lead to additional funding to address this issue.

Barbara said she will be following up with Jon about DES participation.

Kathy said Arizona should apply.

Jon said that Yumi at the Sonoran UCEDD has done a lot of work in this area.

Janna thanked Jon for bringing this opportunity to the committee's attention and to keep the committee posted on next steps.

#### F. Call to the Public

None offered.

# G. Adjourn

The meeting adjourned at 2:01 pm.

Dated this 21<sup>st</sup> day of December 2023 Arizona Developmental Disabilities Planning Council