



Monday,
November 8, 2021`
System Access &
Navigation
Committee meeting
3839 North 3rd Street, Suite 306, Phoenix, Arizona 85012

DRAFT MINUTES

The System Access & Navigation committee meeting of the Arizona Developmental Disabilities Planning Council (ADDPC) was convened on Monday, November 8th, 2021, via Google Meets (virtual). Notice having been duly given. Present were the following members of the ADDPC.

Members Present

Mary Slaughter, Chairperson, Janna Murrell, Raising Special Kids Kin Counts, parent/family Vijette Saari, parent/family Bianca Demara, parent/family	Kathy Levandowsky, parent/family Barbara Plcone, DDD
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Staff	Guests
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Erica McFadden, Executive Director Steve Freeman, Staff	
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A. Call to Order/Welcome

Chairperson Mary Slaughter welcomed everyone to the Arizona Developmental Disabilities Planning Council (ADDPC or Council) System Access & Navigation Committee meeting. The meeting was called to order at 11:01 A.M. Roll call and participant introductions were completed.

**B. Overview of System Access &
Navigation.**

Erica McFadden provided guidance on what feedback the Planning Council is hoping to learn from this committee.

1. What opportunities should we be amplifying, that will support individuals and families. For example, many parents are not aware of the Parent Line that Raising Special Kids has available.
2. Develop a “how to guide” for navigating Arizona’s service system for families and individuals moving to Arizona from out of state and or at the same time develop an information & resource hub that addresses key information related to transition points and specifically addresses underserved communities.

Kin Counts said that it is important to look at what resources are already available for families so that we just add to what is already there.

- Vijette Saari agreed with what Kin Counts said about the resources. Lots of families in the rural areas do not have knowledge about resources available like Raising Special Kids. Health Currents, Arizona Now Pow are developing resource hubs and it would be beneficial that we track how the system works. It is based on social determinants of health.
- Erica McFadden pointed out that would be helpful down the road, but it is something different then what we would be doing here since we are looking at transition points.
- Bianca Demara said that there are many ways to make the resources more parent friendly and a lot more user friendly. Perhaps have it filtered out by age.
- Kathy Levandowsky asked if Erica McFadden if we are going to start by convening a group of families with a lived experience to gather their input first and use that information to help us with all the other activities? Erica McFadden let the committee know that is what was suggested in some of the forums and this committee can decide if that is the way that the strategy that they would like to take? It sounds like how this discussion is going people are really interested in looking at the transition point hub document and seeing what is out there now.
- Barbara Picone shared a link in the chat to Navigating the system for DDD members. Erica McFadden said that document is helpful, but what we heard is we need a checklist by age something that is simpler for families to use.

Mary Slaughter asked Janna Murrell her thoughts on the discussion.

- Bianca Demara asked Janna Murrell if Raising Special Kids (RSK) has a transition into adulthood PowerPoint that is given? Janna let the committee know that yes, they have two. One from middle school to high school and one from high school to secondary education then into adulthood. RSK also has early childhood transition information and legal options once a person turns 18.
- Mary Slaughter talked about her passion for this committee in her friend Ann who she has guardianship of. When her friend turned 80 there was a huge drop off of services that Ann

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- wanted access to such as affordable housing. During that time Mary Slaughter realized that as people with I-DD age and need more resources and they need lots more services. Many of the potential members have never been connected to the DDD system, but the system has no knowledge of them.
- Janna Murrell said that Raising Special Kids does not have a printed guide dealing with transition points. Mary Slaughter mentioned that there is a huge void of services as the consumers age. Barbara Picone said that she will investigate the DDD system and see if there is a way to for a person to move to EPD once they meet the qualifications for DDD and vice versa.

C. Identifying next steps

- Janna Murrell said that she will email over bullet points to the committee on different transition points for early childhood and adult transition, so that this committee can add to the list. Kathy Levandowsky asked if DDD can provide this committee with the number of members in the state who are 50 years of age and older and those members who are 65 plus. Barbara Picone said that she will ask about that information for older adults.
- Erica McFadden stated what happens to the members who do not have an advocate as knowledgeable as Mary Slaughter is? Do they end up on the street homeless?
- Barbara Picone said that any tool that we develop needs to be shared far and wide so that all families have access to the tool not just for families that happen to have a conversation with one of us.
- Janna Murrell suggested that the tool that we develop be along the lines of a findhelpphx.org. It is a tool that Raising Special Kids uses all the time.to be able to help families navigate the system.
- Erica McFadden asked if there is anyone in the group that can volunteer to pull together the checklists that are out there for early childhood or high school transition. or do you have interns available to help? If you can agree to send in the available resources that are already out there would be very helpful.
- Erica McFadden shared that in the past we have tried to pull together families to discuss gaps in the system for older adults. Efforts were not successful.
- Mary Slaughter said that our focus for now is elderly people with I-DD. We can create
 1. A fact sheet
 2. A how to guide
 3. We can interview individuals and their families about their needs
- - Erica McFadden said that it would also be helpful to know from DDD how they handle it when someone turns 65 and they become Medicare eligible? How does it work with their current health plans and what kinds of conversations do they have with their support coordinators during this transition about how the process works?

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- The committee wants to determine what is out there now for families, any guides? Barb has her
- homework; Janna will send out bullet points to the committee. ADDPC can help amplify the housing situation on a regular basis if DDD will provide the information.
- Janna Murrell asked what is our timeline for completion? Erica McFadden stated that we need to have at least one fact sheet and a How to Guide by September 30, 2022.
- Erica McFadden said that she will share a brief that ADDPC put together that deals with the lack of activities for people with DD that are older adults. Currently all that they have is special Olympics and once that is over there is nothing.

D. Who else needs to be Invited

-Kathy Levandowsky suggested that we invite someone from Area Agency on Aging. Erica McFadden will invite Ume. Any others that should be invited let Steve Freeman know with their contact information.

Are there any family members that should be invited to this committee meeting? Be sure to let Steve know of any others that should be invited. StevenFreeman@azdes.gov.

E. Next meeting January 24, 2022, 11:00 A.M.

F. Call to the public

No public

H. Adjourn Janna Murrell moved, and Kathy Levandowsky seconded the motion. The vote was unanimous. The meeting adjourned at 1:31 pm.

Dated this 22nd day of November 2021
Arizona Developmental Disabilities Planning Council