

**Arizona Developmental Disabilities Planning Council  
Annual Focus Group and Follow-Up Survey  
February 2013**

**Background**

A focus group of six Arizona Developmental Disabilities Planning Council (ADDPC) stakeholders was held via phone conference on February 21, 2013 for the purpose of determining what the Council can do to increase its effectiveness. Participants are listed in Appendix 1. An additional invitee submitted written comments. All focus group invitees (17) were sent three additional questions via email following the focus group; five responded. The focus of the current assessment was Federal Fiscal Year 2012 (10/1/11 – 9/30/12).

Results of both the focus group and the written survey are included in this summary. Results will be used to inform discussions during the Council's 2013 planning retreat and to improve Council functioning.

**Focus Group**

The facilitator reviewed the purpose of the focus group, the planned use of results, and the format and ground rules for the discussion. ADDPC Executive Director Larry Clausen provided a summary of the Council's major contracts and outcomes for the last year. Participants were invited to send any questions they have about the ADDPC contracts and other activities to him for response.

Following the Executive Director's report, participants provided their thoughts about what the ADDPC can do to be as effective as possible in carrying out its multiple functions. Following is a summary of the comments, organized by question. These are not verbatim, but reflect each participant's comments in response to the questions.

**1. Goals**

**1.1 Goal Area #1: Self-Advocacy**

**a. What evidence do you see of progress in this goal area?**

**b. What could we do to be even more effective in this goal area?**

- There is a push to engage in self-advocacy, to let the public know what our needs are. Uniting self-advocacy groups is a good direction to go in.
- I am excited about the funded self-advocacy projects and coalescing the self-advocacy groups. Going statewide is good, too. From a health plan perspective, it is hard to access information; there are silos depending on what services/systems an individual is in. We need to make sure everyone has the information that the Council has available. Unless someone is already involved in self-advocacy, they may not know about the Council and its many resources. On the other hand, people are not necessarily sitting around waiting for someone to engage them in self-advocacy; they may already be advocating for themselves—it would be good to identify and support them. There is really no one place to go to identify self-advocates. Some may be working, some may be in community college or university—engaged in groups that are not connected to the disability community. We need to reach them, too.

- The Council has done a nice job of bringing organizations together and not just around funding. The focus on promoting self-advocacy opportunities makes sense. The Council can help organizations with a similar mission to work together and not “bounce off each other.” People seem more willing to come together now than in the past.
- The self-advocacy groups funded by the Council reflect diversity of “ages and stages.” It is good that the focus is not just funding self-advocacy groups, but rather supporting coalition building. That’s a real positive.
- Funding for a self-advocacy conference through the Southwest Institute is evidence of progress.
- In order to be even more effective, the Council needs to get the word out more broadly. My organization has not been aware of the self-advocacy training that is available and we need to be. The Council needs to make sure that its resources are conducive to diverse participation, e.g., videos are captioned. It would be good to link the Council’s resources to other websites, e.g., the Arizona Commission for the Deaf and Hard of Hearing.
- For the future, the Council should consider including a peer mentor model, so more experienced self-advocates and self-advocacy organizations can help their newer peers.
- There is a need in the community for a better understanding of self-advocacy—it is not about telling people what to do, but rather building capacity so that people can voice their own opinions. Peer mentoring would be useful. Many of us who have been in the system feel an obligation to share what we have learned over the years, but some are less motivated to do that—the Council could help to energize them to help others along the path.
- It would be useful for the Council to promote self-advocacy as it relates to health and to facilitate linkages between the self-advocacy alliance and county health department, health plans, etc.

## **1.2 Goal Area #2: Community Integrated Employment**

**a. What evidence do you see of progress in this goal area?**

**b. What could we do to be even more effective in this goal area?**

- The Council-funded membership in the State Employment Leadership Network (SELN) sounds like the Business Leaderships Network (BLN). (The difference was explained. BLN focuses on employers; the Council-funded Untapped Arizona is similar in this regard and will be coordinating with BLN. SELN focuses on government agencies.)
- There are integrated employment policy issues surfacing again. (The Council will evaluate these as they arise.)
- There are limitations on availability of Vocational Rehabilitation services. The Council needs to help identify other resources.
- With respect to young adults, the Council can support their self-advocacy and movement toward community integrated employment.

## **1.3 Goal Area #3: Empowerment through Provision of Information that Promotes Informed Decision Making**

**a. What evidence do you see of progress in this goal area?**

**b. What could we do to be even more effective in this goal area?**

- The visibility of the Council has improved dramatically. The Council is seen as being very professional. Materials reflect the brand. The website has expanded and the Council has a presence in the social media (Facebook). Information provided is data-based and accurate.
- When people in the disabilities community say “the Council,” they are typically referring to the Arizona Developmental Disabilities Planning Council, although there are several other Councils that address the issues of persons with disabilities.
- Partnerships with credible organizations such as the Morrison Institute have been forged.
- The Council has significant resources to share and touches many people. Responses from people who use the Council’s resources are positive.
- We are getting questions about the Council’s resources when we are out in the community, suggesting that people are aware of and interested in using these resources. Self-advocates can help to get the word out about available resources.

## **2. Coordination and Collaboration**

**2.1 What successes have you seen as a result of the Council’s efforts to coordinate and collaborate with other agencies and organizations?**

**2.2 What opportunities do you see for expanding or strengthening relationships and partnerships with other Councils, government agencies, and/or community-based organizations?**

- Successes include the Project Search collaboration and funding for a self-advocacy conference for youth/young adults through the Southwest Institute.
- Some Council members are getting more involved nationally. There may be similar opportunities for the Council as a whole.
- As the self-advocacy alliance forms, there will be many opportunities for enhancing coordination and developing collaborations with a variety of self-advocacy organizations representing diverse constituencies. Some of these groups may not be focused on *developmental* disabilities, but might be more broadly representative. Interlocking memberships could expand influence.
- AHCCCS health plans are required to have a member advisory council. The self-advocacy alliance could have a link to them.
- Family and self-advocate (including young adult) involvement is critical. Efforts should be made to reach more of these individuals in order to build their capacity and the capacity of the Council.
- The Council needs to do succession planning, so that there are new Council members ready to step in as current members phase out over time.

## **3. Overall**

**3.1 What do you think has been the greatest accomplishment/contribution of the Council during this past year?**

- Increased visibility statewide (2 participants noted this)
- Bringing self-advocacy organizations together to talk about their issues and set goals and objectives
- Electronically accessible and relevant information that people can use (this has “raised the bar” in terms of the Council’s credibility)

### **3.2 What is the most important thing for the Council to consider doing in the coming year?**

- Succession planning
- Increase diversity of the Council's membership (2 participants noted this)
- Link interested self-advocates to positions on boards, committees, etc.
- Engage self-advocates in healthcare advocacy; ensure that information about healthcare changes is provided to self-advocates; lots of changes that will impact them are coming soon (2 participants noted this)

### **3.3 What could the Council do to continue to reach unserved/under-served populations in the state?**

### **3.4 What could the Council do to continue to reach diverse populations?**

- Reach the Latino community, particularly those who are monolingual Spanish speaking, via targeted outreach
- Look at what is being done via the Affordable Care Act and Maternal and Child Health (Title V) to reach the Latino community (e.g., conference conducted in Spanish, with follow up)
- Ask advocacy groups what they have done to reach unserved/under-served populations that has been successful and what the barriers have been; work with advocacy groups that focus on these populations

## **Survey**

Following is a summary of the responses to the follow-up email survey. Percentages should be used with caution due to the small number of responses. Data from previous years' surveys are included for purposes of comparison.

### ***Impact***

1. Council activities have improved the ability of individuals with developmental disabilities and family members to make choices and exert control over the services and supports they use.

<b>RESPONSE</b>	<b>2012 (N=5)</b>	<b>2011 (N=7)</b>	<b>2010 (N=7)</b>
<b>Strongly Agree</b>	4 (80.0%)	1 (14.3%)	1 (14.3%)
<b>Agree</b>	1 (20.0%)	3 (42.9%)	3 (42.9%)
<b>Agree Somewhat</b>	0 (0.0%)	3 (42.9%)	2 (28.6%)
<b>Disagree Somewhat</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>Disagree</b>	0 (0.0%)	0 (0.0%)	1 (14.3%)
<b>Strongly Disagree</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)

Comments (from the focus group):

- The Council has done a nice job of developing resources, including the website. Once people know about resources, they will feel more confident to pursue what they want. The Council validates them.
  - The Council needs to reach a broader audience.
2. Council activities have improved the ability of individuals with developmental disabilities and family members to participate in community life.

<b>RESPONSE</b>	<b>2012 (N=5)</b>	<b>2011 (N =7)</b>	<b>2010 (N =7)</b>
<b>Strongly Agree</b>	4 (80.0%)	2 (28.6%)	0 (0.0%)
<b>Agree</b>	1 (20.0%)	3 (42.9%)	3 (42.9%)
<b>Agree Somewhat</b>	0 (0.0%)	2 (28.6%)	3 (42.9%)
<b>Disagree Somewhat</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>Disagree</b>	0 (0.0%)	0 (0.0%)	1 (14.3%)
<b>Strongly Disagree</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)

### **Satisfaction**

3. Council activities promote self-determination and community participation for individuals with developmental disabilities.

<b>RESPONSE</b>	<b>2012 (N=5)</b>	<b>2011 (N =7)</b>	<b>2010 (N =7)</b>
<b>Strongly Agree</b>	3 (60.0%)	1 (14.3%)	0 (0.0%)
<b>Agree</b>	2 (40.0%)	4 (57.1%)	4 (57.1%)
<b>Agree Somewhat</b>	0 (0.0%)	2 (28.6%)	2 (28.6%)
<b>Disagree Somewhat</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)
<b>Disagree</b>	0 (0.0%)	0 (0.0%)	1 (14.3%)
<b>Strongly Disagree</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)

**Appendix 1**  
**Focus Group Participants**

Beca Bailey, Arizona Commission for the Deaf and Hard of Hearing

Angela Denning, Arizona Department of Education

Tony DiRienzi, Statewide Independent Living Council

George Garcia, Southwest Institute for Families and Children

Marta Urbina, Arizona Department of Health Services, Office for Children with Special Health Care Needs

Judith Walker, United Health Care

B. J. Tatro, B. J. Tatro Consulting, Facilitator