

Self-Advocacy Trainings for Latino Adults with Disabilities and their Families

YUMA, ARIZONA



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INTRODUCTION

*“When you see other people with problems you feel less alone.”
– Caregiving parent of an adult with a disability*

Phoenix is a large metropolitan city with considerably more resources available for individuals with disabilities compared to Arizona’s rural communities. Arizonans in rural communities can have a hard time finding disability services because provider networks are scant, and large distances can deter people from seeking the care they need. This is especially difficult in Arizona as [disability transportation systems](#) are seen as unreliable.

Arizona’s noninstitutionalized disability population is 30 percent more likely to live in poverty than individuals without disabilities, and Arizona is ranked 30th in the nation for disability employment, with only 21 percent taking part in the workforce.¹ Furthermore, 21 percent of all individuals with disabilities in Arizona are Latino. Latinos with disabilities in Arizona face additional challenges in accessing disability resources, stemming from a lack of information, language barriers and social exclusion.

In 2016, the Arizona Developmental Disability Planning Council (ADDPC) funded Arizona State University’s Morrison Institute for Public Policy to conduct a six-week self-advocacy training for Latinos adults with disabilities and their caregivers. This pilot training in Phoenix had six guest speakers present on disability resources, and provided informational training exercises about self-advocacy. The exercise was successful in condensing and disseminating applicable self-advocacy information to adults with disabilities and their caregivers. Participants reported that the training helped them build confidence, a sense of empowerment and individual relationship-building skills. Adults with disabilities did not, however, demonstrate an increase in their individual levels of autonomy and self-realization. To address self-realization and autonomy issues, and target an underserved community, this year’s self-advocacy training was hosted as an intensive two-day seminar in Yuma, Arizona. Yuma was selected by ADDPC because it is considered one of Arizona’s underserved communities and its population is 60 percent Latino.²

This study is modeled after the Alzheimer’s Association’s Project Esteem, which provides individuals with disabilities and their families an outlet to share and learn from each other through facilitated information sessions and support. The goal of the second year of the training is to assist Latino families in creating a peer support network while learning and empowering individuals to self-advocate.

A recent study found that many parents and relatives of individuals with disabilities prefer to have professionals advocate for them, as opposed to family members. However, professionals may be less comfortable advocating on behalf of an individual with a disability

¹ American Community Survey. 2011-2016. Five-year sample.

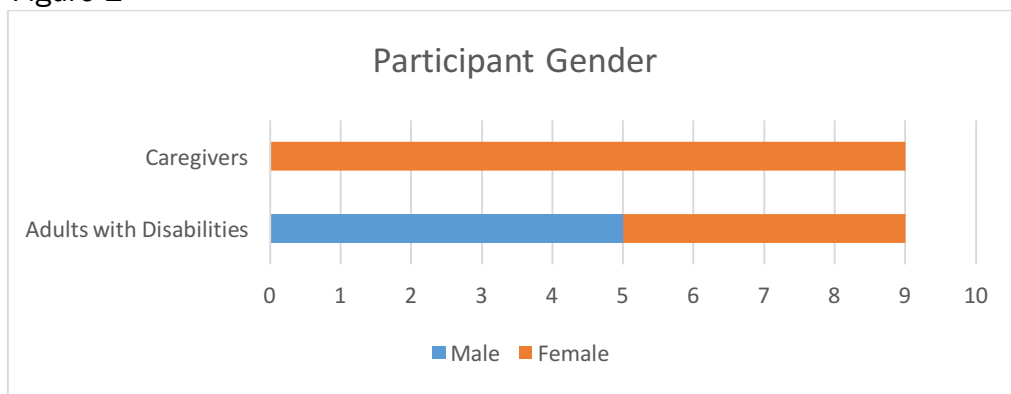
² City-Data. Yuma, Arizona. 2016 <http://www.city-data.com/city/Yuma-Arizona.html>

due to a lack of training,³ and low-income families do not have the financial means to pay someone to advocate on their behalf. Research has shown that parents are natural advocates for their children. However, due to a lack of understanding of laws and available services, many families with individuals with disabilities remain uninformed of services that may be available to them.

WHO PARTICIPATED?

The goal of this training was to disseminate information about disability providers in Yuma, and foster self-advocacy skills in Latino families that have adults with disabilities. Morrison Institute’s research team recruited 18 participants – nine adults with disabilities and nine caregivers – and administered three assessments to each individual. The pre-assessment was administered before the training, the post-assessment was given at the end of the second day of the seminar, and a maintenance-assessment was administered through a six-week follow-up call. All caregivers were female; five adults with disabilities were male, and four adults with disabilities were female (Figure 1). Of the individuals with disabilities in this study, eight have intellectual disabilities and one has a physical disability.

Figure 1



Morrison Institute for Public Policy, n=18

WHAT DID WE DO?

The format for the two-day seminar was as follows:

1. Guest speakers from three nonprofit organizations in Yuma presented the following topics in Spanish to all participants:
 - How to self-advocate for their rights
 - Employment, volunteerism and employer expectations
 - Seeking and navigating resources
 - The construction of social supports and connections

³ Burke, M. M., Goldman, S. E., Hart, M. S. and Hodapp, R. M. (2016), *Evaluating the Efficacy of a Special Education Advocacy Training Program*. *Journal of Policy and Practice in Intellectual Disabilities*, 13: 269–276. doi:10.1111/jppi.12183

- Planning for the future
 - Relationships and romance
2. After each presentation there was a 30-minute group discussion with all 18 participants.
 3. Adults with disabilities were then separated from their caregivers and two separate focus groups were held. Both group discussions were facilitated by Morrison Institute staff and research assistants in an open narrative style, giving adults and caregivers an open space to discuss their experiences.
 - a. These smaller group sessions asked more in-depth questions, seeking to understand individual fears that each participant has when they think about planning their future and the future of their counterpart in the other room.
 4. All participants took a pre-, post- and maintenance assessment that measured their level of empowerment, engagement in social and ability to self-advocate.

How was self-advocacy measured?

In order to measure self-advocacy four assessment tools were used:

- [ARC Self-Determination Scale](#)
 - The ARC assessment identifies each participant's strengths and weaknesses, and assesses the relationship between the participant's ability to self-advocate and their level of self-determination. Psychological empowerment, self-realization, and autonomy assessments are evaluated in this study.
- **Social Networks**
 - The second assessment tool asks participants for their basic demographic information, the types of social media accounts they have, and how often they use social media as a tool to connect with people in their communities.
- **Knowledge of Disability Service Providers**
 - Both individuals with disabilities and caregivers were asked about their knowledge of disability service providers in their area.
- **Self-Advocacy**
 - Self-advocacy was framed as a pathway for individuals to speak up for themselves through understanding their rights. Participants answered five short-answer questions focused on each individual's knowledge of self-advocacy, their ability to self-advocate and their success rate when self-advocating.

Assessment materials were updated from the pilot study so that all questions were in Spanish. Another change to last year's study was that more pre-assessment questions were asked over the phone so that there would be additional time for presenters and group discussions on day one of the seminar. To read a more extensive explanation of the assessments used, please refer to the 2016 self-advocacy study.

RECRUITMENT AND SCREENING

The recruitment process started six weeks before the event with a radio advertisement on one of Yuma's Spanish radio stations. After two weeks the radio announcement had not attracted any participants, so Morrison Institute reached out to Yuma's Regional Center for Border Health (RCBH) to help recruit participants. RCBH is a well-respected nonprofit organization with strong community contacts, and they spread the word about the event through their networks and their walk-in-clinic. After all 20 participants were recruited, RCBH also helped secure the Goodwill Training Center for the event, found local Spanish-speaking leaders to present and provided volunteer support during the seminar.

As respondents called in to sign up for the training, a basic questionnaire and consent document were completed over the phone. Two adults with disabilities were unable to complete the questionnaire over the phone, and their legal guardian answered the questionnaire and consented on behalf of the adult with a disability. After each screening, participants were asked if they had any transportation barriers that would prohibit them from attending the seminar. Three of the nine families required transportation support, and Morrison Institute research assistants scheduled taxis for all participants unable to travel to the event independently. One family did not show up to the seminar, leaving 18 total participants in this year's training.

CONSENTS AND STIPENDS

Respondents agreed to participate in the study through a verbal consent process during the pre-screening phone call. Participants then signed a written consent to participate in the study on the first day of the seminar. Legal guardians signed consent forms for adults with disabilities that were unable to sign for themselves. All consents were available in English and Spanish. All participants chose to have their consent read to them in Spanish.

The consent process also detailed participant stipends. Participants were informed that they would each receive \$100 a day for both days of the training, but that they would only be paid \$50 for the first day if they did not attend the second day. Participants were also notified that they would receive a follow-up phone call six weeks after the seminar, and that each participant would receive \$50 for the successful completion of the maintenance assessment.

FINDINGS

The response rate for all pre-, post- and maintenance assessments was 100 percent.

ARC Self Determination

The 2017 ARC Self Determination scores showed similar trends for adults with disabilities in pre-, post- and maintenance scores as the 2016 study. Self-realization and autonomy scores stayed the same or diminished after the maintenance assessment, ranging from 64 percent

to 57 percent, and psychological empowerment improved considerably, ranging from 76 percent to 86 (Figure 2). autonomy also after assessments, 66 percent to

Assessment	Level of Psychological Empowerment	Self-Realization	Autonomy
Pre	76%	64%	66%
Post	76%	56%	65%
Maintenance	86%	57%	61%

percent Levels of went down maintenance ranging from 61 percent.

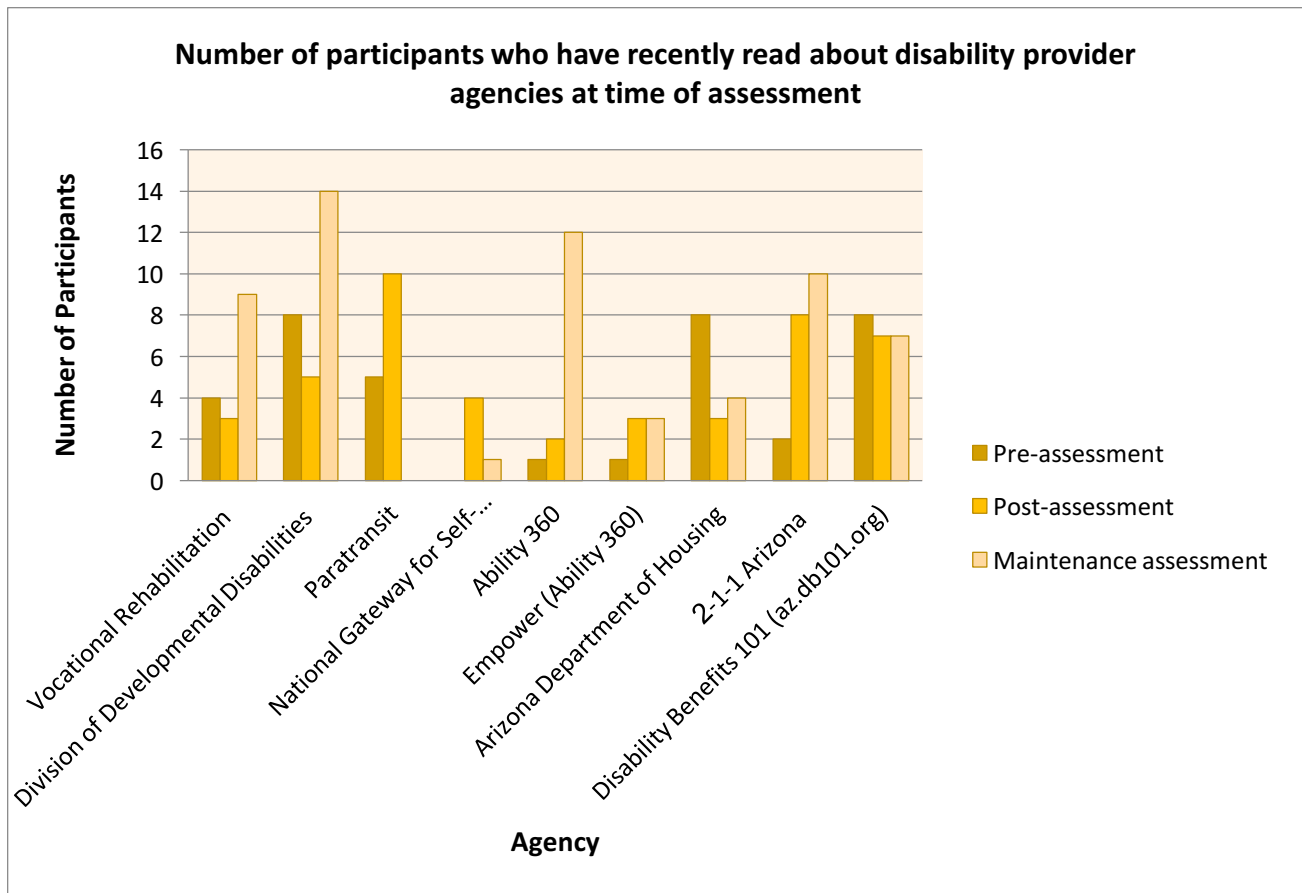
Figure 2

Morrison Institute for Public Policy n=9 participants

Knowledge of Disability Service Providers

Overall, participants increased their knowledge of disability resources by reading more about disability agencies. Figure 3 shows how many resources participants had recently read about disability agencies. The number of resources participants read about went up at either the post- or maintenance assessments for all agencies except for the Arizona Department of Housing and the Disability 101 website.

Figure 3



Morrison Institute for Public Policy, n=18 participants

At pre-assessment, participants said that there is a lack of knowledge about disability resources and providers in their community, despite the adults with disabilities having gone through the U.S. education system. Several participants felt like schools should be doing more to prepare students for a transition out of school, and one adult with a disability said it was because “teachers do not have eyes for talent.” In a post-seminar survey, participants said they learned a lot from the seminar about the types of resources available to them. One caregiver commented, “If I would’ve known about these resources I would’ve done things differently.”

Social Networks

Adults with disabilities created one new Snapchat account and two new texting accounts between the pre-assessment and the maintenance assessment (Figure 4).

Figure 4

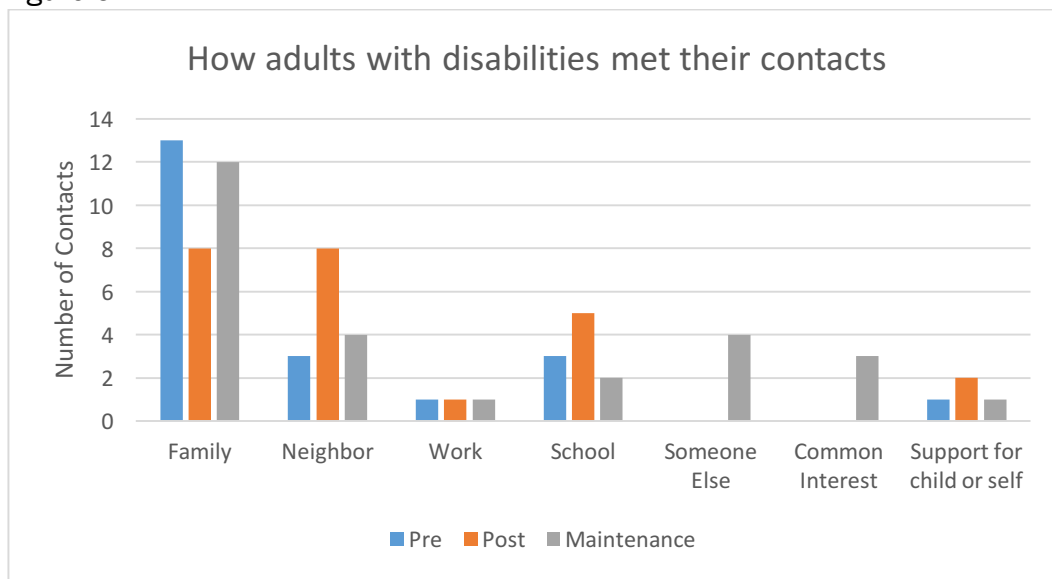
Number of Participants with Social Media Accounts			
Assessment	Facebook	Snapchat	Text
Pre	3	0	2

Post	2	0	4
Maintenance	3	1	4

Morrison Institute for Public Policy n=9 participants

Participants with disabilities started with 21 individuals in their social networks and at the time of the maintenance assessment they had increased that number to 27, which is a 29 percent increase in their total social network. The way in which participants met the people in their social networks also changed. Most notably, there were seven new contacts that came from meeting someone “through a common interest” or “someone else.” (Figure 5) This could be related to the networks created at the training seminar because during the maintenance-assessment calls all participants said that they are still in touch with at least one other participant from the self-advocacy training.

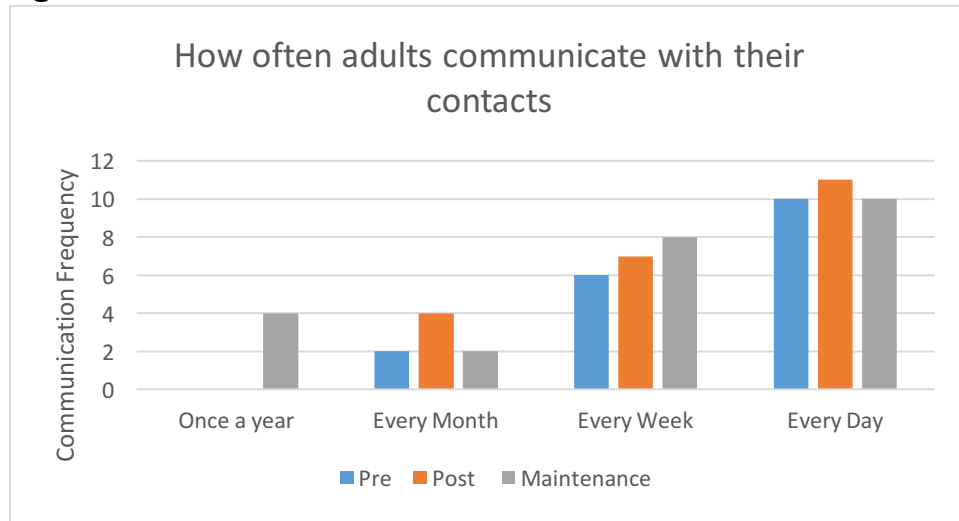
Figure 5



Morrison Institute for Public Policy n=9 participants

The frequency in which adults with disabilities communicate with their social networks also increased after the post-assessment for communications that take place every day and every month. Communication frequency increased at the maintenance assessment for participants who speak with their contacts once a year and weekly (Figure 6).

Figure 6



Morrison Institute for Public Policy n=9 participants

Self-advocacy

Pre-assessment results show that seven adults with disabilities did not have sufficient information to self-advocate. Many participants cited a lack of understanding of self-advocacy, or how self-advocacy could be used to meet their needs independent of their caregivers. Seven of nine adults also said that they did not have confidence in their ability to successfully self-advocate when they had the opportunity.

Maintenance-assessment results indicate that six adults with disabilities had a better understanding of self-advocacy and how they could use it in various settings to get what they need. During the maintenance-assessment six adults said they now have the ability to reach their goals, and they feel more empowered. One participant commented, “This group has given me the power to insist.” Caregivers also expressed a desire to further advocate for the adults with disabilities in their lives. One caregiver was unhappy with the services she was receiving from a local agency and she asked, “Where can I file a complaint?”

Break-out discussions

Participants expressed a sincere desire to share their personal experiences in group settings despite potential stigma associated with discussing behavioral health issues in public. Both

adults with disabilities and their caregivers shared concerns about the future livelihoods of the adult with a disability in their family if something were to happen to their caregiver. Adults with disabilities also were asked about their individual goals and dreams. Seven adults had dreams of doing things that they already do on a daily basis such as: cooking, sports, art, cleaning their room, and school. Two participants wanted to learn how to help others in similar situations as themselves.

Of the nine participants with a disability, one is presently working, one is studying at a community college and four are involved in extracurricular activities. Adults with disabilities said they want to be independent, and many of them recognize that they could achieve independence through work. Seven adult participants who are not working and not actively searching for employment still expressed a desire to have a career because it would ensure financial stability that would make their caregivers more comfortable. Adult participants also wanted to learn new skills independently of their caregivers, especially in the field of technology.

LIMITATIONS AND DISCUSSION

At the end of seminar, a satisfaction survey was completed with each participant. Key themes and recommendations from participants included:

1. Future self-advocacy trainings should have a guest speaker that has a disability.
2. Assessment instruments should be tailored toward “quality of life questions.”
3. Researchers should create a platform or contact list after the first day of the seminar so that participants can continue communicating after the training.
4. Future self-advocacy trainings should tailor assessments to meet the timeframe of the instruction provided. It is difficult to expect changes in enrollment in disability programs and self-realization scores from a two-day training.
5. Caregivers wanted to know more about the following topics:
 - a. How they can teach others in their community about self-advocacy
 - b. Prevention of physical and emotional abuse of the adults with disabilities in their family

CONCLUSION

This self-advocacy training improved scores in self-advocacy, knowledge of resources, psychological empowerment and social connections for adults with disabilities. Self-realization and autonomy did not increase at the time of the maintenance assessment, and in fact scores decreased. These findings are similar to results from the pilot training in late 2016, which raises the question: Do individuals feel more empowered and willing to self-advocate after the training, but then feel discouraged when they try to self-advocate and are unsuccessful?

Effective self-advocacy is the ability to navigate a situation in which a person of power prevents access to a needed resource. Learning to be self-sufficient through self-advocacy efforts takes time, and more frequent trainings could help individuals learn how to mentally

recover and respond to authority figures that tell them they cannot have access to the goods and services they need.

The self-advocacy training in Yuma built a strong connection among participants, as all participants are still in communication with at least one other adult and caregiver that attended the seminar. Participants also had a get-together at one family's home and all 18 participants attended. Participants did not, however, use other participants as resources and referral agents to get them into new community resources. Instead, they opted to use their time together to create friendships and stay socially engaged.

Through satisfaction surveys at the end of the seminar and through general feedback, participants repeatedly said that the group was very helpful to them, and this sentiment continued through follow-up calls. All participants asked Morrison Institute staff to notify them of future trainings because they wanted to stay involved. Participants did not express interest, however, in a future leadership training or in joining a governing board or commission. Due to the strong sense of community created amongst participants, the lack of interest in leadership activities is most likely due to time constraints and transportation challenges that face families with disabilities.

All participants who attended this seminar have different skills, knowledge and abilities that enable them to access community resources. Increased connectivity among individuals with disabilities creates a social network that allows individuals with disabilities and their families to share what worked best for them when it comes to self-advocacy. Several participants cited persistence and increased questions as imperatives to getting what they need. Some caregivers provide extensive supports to the individuals with disabilities in their life in an effort to help them reach independence; however, the acuity of an adult's intellectual disability can play a large role in their ability to self-advocate.

Regardless of disability, each caregiver and individual with a disability has problem-solving abilities. Through increased meetings, communication and social network connectivity, individuals with disabilities and their families can teach each other to solve similar problems.

In the closing remarks of the maintenance assessment, one adult participant shared thoughts about the self-advocacy training: "I learned a lot of information, and it was great to meet these other people. I feel like a family was created."

INFORMATION

Additional information about available resources for individuals with disabilities in Arizona can be found at ADDPC's resource website: <https://addpc.az.gov/resources>

