Training Latino Families to Self-Advocate Effectively: Empowering Individuals with Disabilities and their Families

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ARIZONA **DEVELOPMENTAL DISABILITIES PLANNING COUNCIL**℠

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Arizona State University

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Introduction

The Arizona Developmental Disabilities Planning Council (ADDPC) allocates funding to research and evaluation projects in Arizona for individuals with developmental disabilities. The Council's strategic goals are to increase inclusion, empowerment and employment outcomes for all individuals with disabilities.

In 2015, ADDPC contracted Arizona State University's Morrison Institute for Public Policy to create and evaluate a six-week self-advocacy training for Latino families living with disabilities. The objective of the training is to instill self-advocacy knowledge in Latino communities so that individuals with disabilities are able to stand up for themselves and achieve their full potential.

Latinos represent 31 percent of Arizona's population, of which 24 percent aged 18-64 live in poverty, and 150,162 have a disability.[12] Latino families that include an adult individual with a disability face unique and significant challenges. All families with disabilities face obstacles when accessing healthcare, transportation, interpretation services and social support networks. However, discrimination, disenfranchisement, poor self-esteem, lack of community resources, and limited knowledge of existing resources can cause further feelings of isolation in Latino families.

The self-advocacy training used in this study was 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 and support. The goal of Morrison Institute's adaptation of this technique is to develop a peer support network that can be used to teach and promote individual empowerment through self-advocacy.

This study piloted six weeks of self-advocacy training in fall 2016 to help support Latino families that do not have sufficient access to resources or information regarding community supports. The Latino self-advocacy training created a space for adults with disabilities and their family members to build connections with other community members.

The training bolstered knowledge of individuals' rights and increased their ability to advocate for themselves.

Who participated, and what did we do?

Latino families in Maricopa County with adults who have disabilities were recruited for this self-advocacy training through Spanish radio station KNUV 1190 AM, and through fliers distributed by the local nonprofit Chicanos Por La Causa. Fliers and ads noted the topics that would be covered in the self-advocacy training, the $250 stipend for each participant and a contact phone number. Ten families were recruited in response to these solicitations. Each individual received additional information about the study and signed a consent form before participating in the training.

The curriculum for the six-week training session was based on materials from three different sources:

- Notes and transcripts from focus groups conducted by Morrison Institute in 2015 with adults with developmental disabilities in rural and underserved communities in Arizona
- This is *MY Life* curriculum
- *SUSTAIN*: A Network Model of Category Learning

The *MY Life* and *SUSTAIN* curricula provided an overarching framework for the facilitation of small group work. Additionally, families in the six-week training were asked what they needed in order to attain their goals.

Morrison Institute staff scheduled transportation for eight families that could not travel to the trainings independently. Guest speakers were scheduled for all six training sessions, and presentations were in Spanish. Interpreters were on-site at all times in case clarification was needed. English and Spanish printouts were available for all presentations. After each presentation adults with disabilities were separated from their caregivers into smaller focus groups. Bilingual facilitators and co-facilitators were present in both groups, moderating discussions about individual home-life experiences.

There were 20 total participants in the six-week Latino self-advocacy training: 10 adults with disabilities and 10 family or friends who acted as caregivers. Of these participants 12 (three adults with disabilities and nine family members) were female and the other eight were male. Seven of the 10 adults with disabilities (four males and three females) completed all three pre-assessment, post-assessment and maintenance assessment survey questions. Six of the 10 caregivers completed all three rounds of surveys (five females, and one male).

Figure 1: Participants and number of participants that completed all assessments

	Adults with Disabilities	Caregivers
Number of Participants	10	10
Number of Participants that completed all assessments	7	6
Male	4	1
Female	3	5

Morrison Institute for Public Policy / Yuma Self-Advocacy Training, 2017

How did we measure self-advocacy?

For the purpose of the self-advocacy training, self-advocacy was defined as an individual's ability to know their rights and speak up for themselves. In order to measure individual self-advocacy, participants completed three assessments throughout the course of the project. The pre-assessment was administered in person prior to the

beginning of training. The post-assessment was given to all participants within one week of completing the sixth training session. The maintenance assessment was given six weeks after all group sessions concluded.

These evaluations used four tools to evaluate each individual's self-confidence, ability to speak up for themselves, map their social networks and use their contacts to communicate and get what they need from the outside world:

1. **The Arc's Self Determination Scale**

The Arc's Self-Determination Scale assessed each adult participant's sense of autonomy, psychological empowerment and self-realization. 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. Study facilitators asked questions from the following sections of the Arc's Self-Determination scale: autonomy, psychological empowerment and self-realization. Long-answer questions from the scale were excluded for reasons of time. Scores were analyzed individually and then aggregated to better understand the overall self-determination level of the group.

2. **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. Research has shown that a major determinant in an individual's ability to self-advocate is the size of their social networks.[3] The assessment includes a social connections mapping exercise in which the participant is asked to name everyone in their social network, the frequency in which they interact with that person, how they met and whether they use these contacts to get things they need.

3. **Knowledge of Disability Service Providers**

Both individuals with disabilities and caregivers were asked about their knowledge of disability service providers in their area. The service provider list included nine total resources from national, state and local disability resources.

4. **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.

What did participants already know about self-advocacy?

Pre-assessment results
Morrison Institute staff found during the pre-assessment that many caregivers and adults with disabilities were unable to express what self-advocacy means to them. Caregivers knew they needed help to improve the independence of the adults with

disabilities in their lives; however, the majority of caregivers were not aware of the resources or steps necessary to start the process of fostering individual independence or self-advocacy.

Figure 2 shows the combined autonomy level for the group. Seven adult participants responded to all three assessments, and one adult responded only to the pre-assessment. Data from Figure 2 shows that overall levels of autonomy and self-realization remained relatively similar between the pre-assessment and maintenance assessment. The group's level of psychological empowerment, however, trended upward increasing by 15 percent from the pre-assessment to the maintenance assessment.

Figure 2

Arc Self-Determination Scale			
Section:	Pre-Assessment	Post-Assessment	Maintenance Assessment
Level of Autonomy	60%	68%	57%
Psychological Empowerment	71%	76%	86%
Self-Realization	84%	82%	84%

Morrison Institute for Public Policy[1]
Yuma Self-Advocacy Training, 2017
n=8 for pre-assessment and n=7 for post and maintenance assessments

Results

Eight of the 10 adults with disabilities completed the social networking portion of the assessment. Participants then listed all the people they know, how they usually communicate with them and how frequently they communicate with each person listed. Results indicated that 46 percent of the time adults with disabilities communicate either in person or on the phone, 20 percent of the time communication occurs online, 9 percent of the time via texting, and 25 percent through both offline and online methods.[2]

All participants also were asked how often they communicate with people in their social networks. Figure 3 shows how often participants communicate with the social contacts they listed. Over half of all communications only take place once or twice a year.

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[1] Percentages are derived from the aggregate responses to seven questions from each section of Arc's Self-Determination Scale, and divided by the total number of points possible in Arc's Self-Determination scale.
[2] n=65 responses. Each participant had the option to list five people; however, some listed less than that. Between the pre, post, and maintenance-survey, some of the contacts may have been listed more than once.
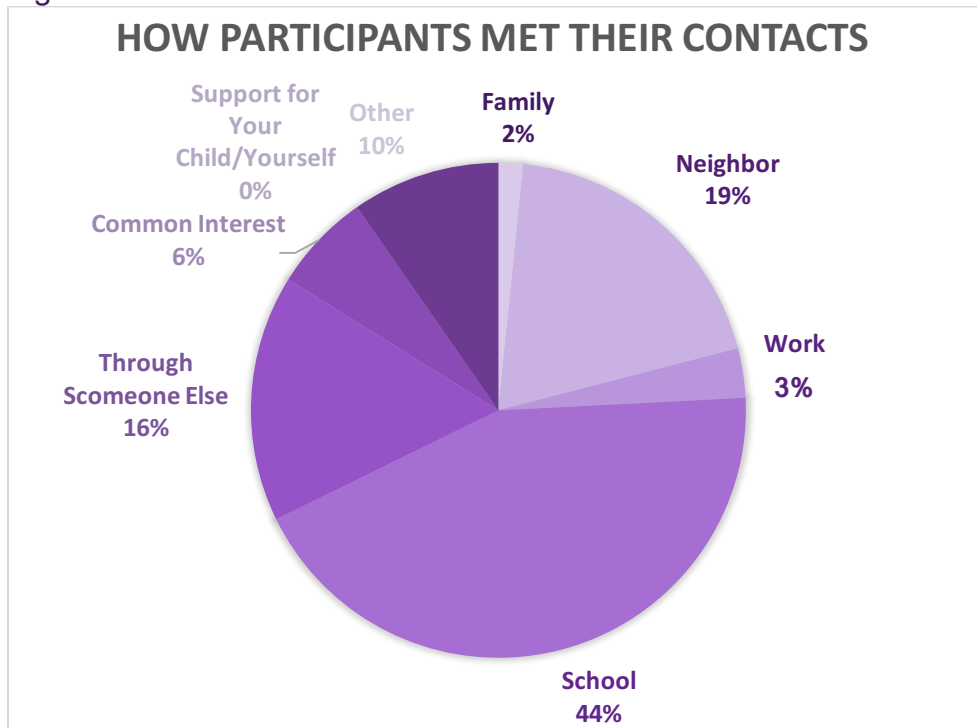
Figure 3

How Often Individual's Communicate with Their Networks
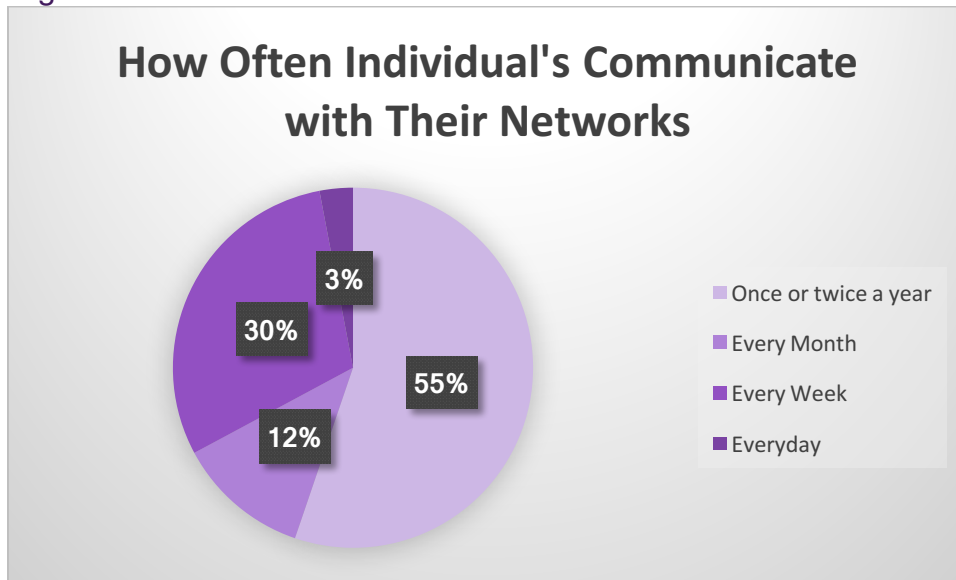
Morrison Institute for Public Policy
Yuma Self-Advocacy Training, 2017, n=67

Participants then described how they met their contacts. For the most part, participants listed friends, classmates, co-workers, previous or current neighbors and people they met through church. Figure 4 shows how eight adults with disabilities met the people they listed in their social networks. The majority of adults said they met their contacts in school. The next most common location for meeting people was in their neighborhood, closely followed by being introduced through someone else. Many of the responses categorized as "other" were because the individual met their contact through church. The next most common write-in answer was video games.
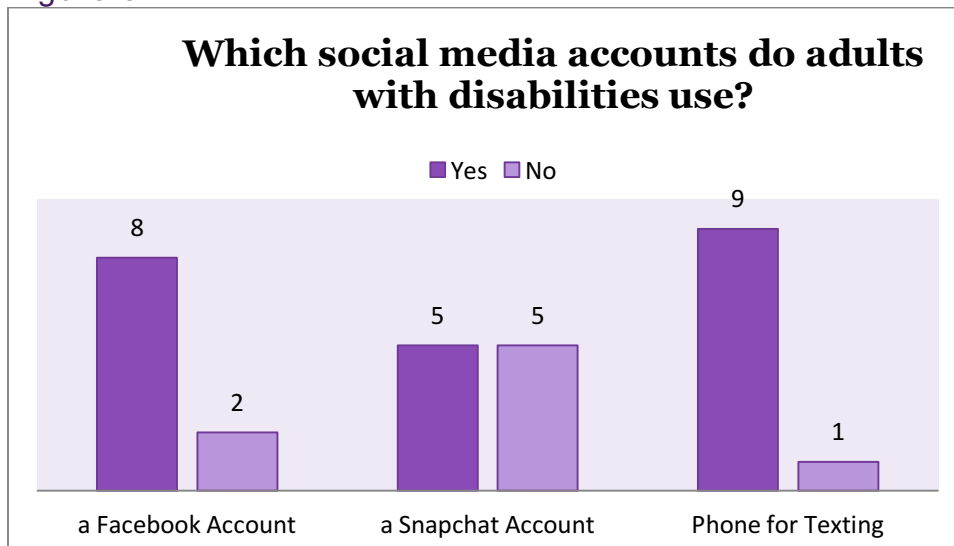
Figure 4

HOW PARTICIPANTS MET THEIR CONTACTS

Support for Your Child/Yourself 0%
Other 10%
Family 2%
Neighbor 19%
Common Interest 6%
Through Scomeone Else 16%
Work 3%
School 44%

Morrison Institute for Public Policy
Yuma Self-Advocacy Training, 2017, n=67

Adults with disabilities also were asked to list the social media accounts they use. Figure 5 shows how many adults have a Facebook, Snapchat, and/or phone and texting account. Facebook and phone and texting accounts had the greatest coverage among all adult participants.

Figure 5

Which social media accounts do adults with disabilities use?

■ Yes ■ No

	a Facebook Account	a Snapchat Account	Phone for Texting
Yes	8	5	9
No	2	5	1

Morrison Institute for Public Policy
Yuma Self-Advocacy Training, 2017, n= 10

Post-assessment results
Of the 20 initial participants, 11 completed all three rounds of the pre-, post- and maintenance-assessments about individual knowledge of agencies that can assist people with disabilities. Figure 6 illustrates participant responses. Between the pre-assessment and the post-assessment, all participants read more about provider agencies in their area, and participants researched 50 new agencies in total. Paratransit, Empower (Ability 360), Arizona Department of Housing, and Disability Benefits 101 (az.db101.org) saw an increase in the number of participants that read about their agency between the post-assessment and the maintenance-assessment.

Figure 6

Number of participants who read about agency resources
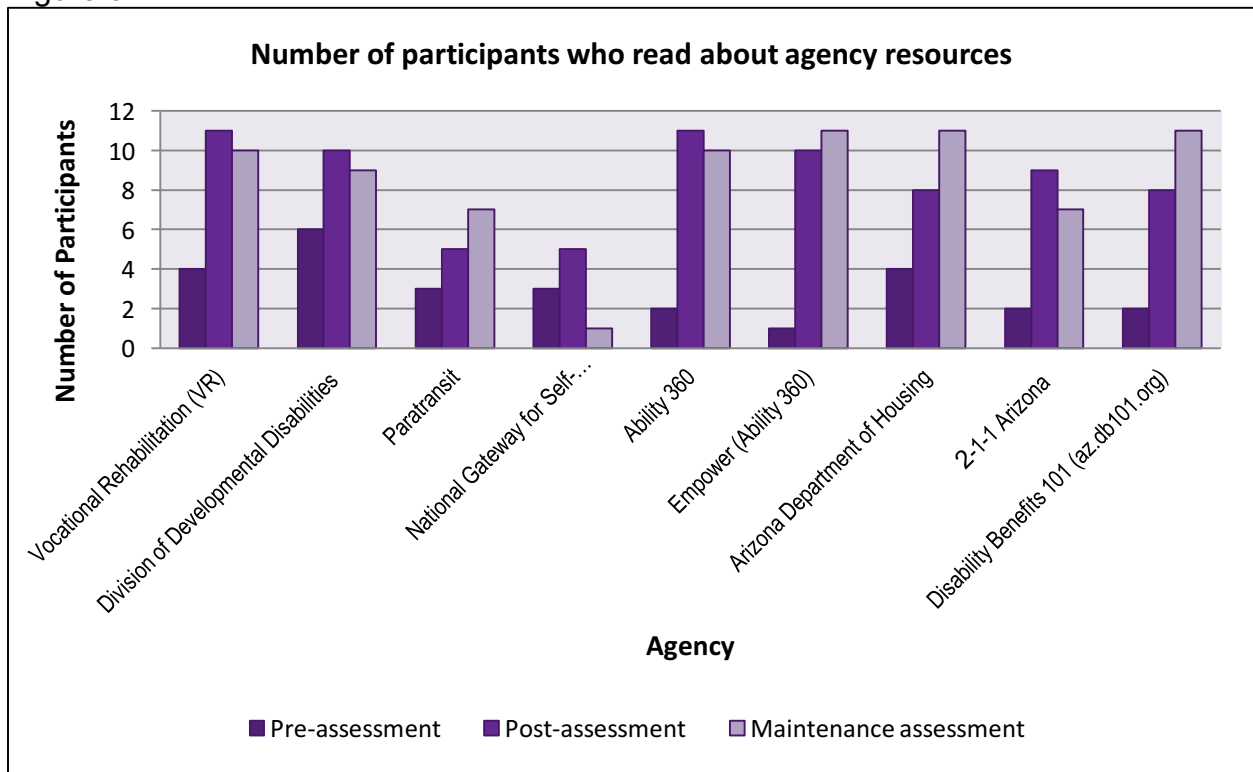
Morrison Institute for Public Policy
Yuma Self-Advocacy Training, 2017, n=181 total responses from 18 participants

Did the self-advocacy training improve participants' ability to self-advocate?

Maintenance-assessment results
After completion of the six group sessions there were two adults with developmental disabilities who were still going to their families for decision-making issues. Based on the maintenance assessment, participants felt that group work helped them with common areas of self-advocacy, such as navigating grocery stores and talking to people in their neighborhoods. One participant said:

> *"When people obstruct the sidewalk I have asked them to clear the area to be able to go through with my wheelchair."*

A few individuals with disabilities said they felt more informed and that they felt empowered to self-advocate:

"I can defend myself and there are laws that protect me."

Participants also were more aware of community organizations and how to contact them:

"Depending on the situation, I can go to the agency that helps individuals with disabilities. If the situation is small, I can defend myself."

Some individuals also felt the groups helped them reach their goals:

"Before the sessions, I did not have enough information to reach goals, now I do."

Based on participant feedback through assessments, both adults with disabilities and their caregivers felt there were many positive takeaways from the six self-advocacy sessions.

How can trainings be improved?

Due to the nature of radio recruitment, all participants were strangers on the first day of the training. It took time for meaningful discussions to evolve because focus group questions asked participants about personal experiences in their home life. Group discussions became more engaging after participants built a level of trust among one another. Despite differing developmental disabilities in each household, families eventually shared stories and identified similarities among themselves. Ice-breaker activities and a condensed training schedule with fewer sessions and more time for networking might help create a trusting environment faster. One major asset to the open communication was the presence of both Spanish and English interpreters and the availability of translated materials.

After the training an evaluation form was administered to all participants. The evaluation form sought suggestions for future discussion topics for focus groups including general feedback about trainings, presentations and focus group structures. Overall, participants felt that despite the availability of written information about disabilities in Spanish, there is still a need to expand existing community supports and networking group opportunities in both English and Spanish. Participants expressed the need for continued information sharing, and they maintained a strong desire for future networking opportunities to be made available in Spanish. Participants also recommended community members who could potentially help lead future training opportunities.

Discussion

The goal of this project was to develop a peer support network in order to teach and promote individual empowerment through self-advocacy. This pilot Latino self-advocacy training attempted to diminish language barriers that prevent non-English-

speaking individuals with developmental disabilities and their caregivers from accessing information about available resources in their communities.

Two adults with disabilities still relied on family members to help them make decisions after the training ended. One reason for this continued support could be the severity of their intellectual disability. Another potential reason was observed repeatedly in both training discussions and assessments: Latino culture places a strong emphasis on family. Autonomy and self-realization group scores did not increase after the maintenance assessment like in the psychological empowerment section, but rather returned to pre-assessment levels. Future trainings could offer continued self-advocacy sessions to see if autonomy and self-realization increase after self-confidence is built-upon over time. Both adults and caregivers also expressed interest in staying engaged and attending future events because the trainings helped them meet other people with similar challenges.

Conclusion

Assessment results indicate that this study's six self-advocacy trainings were successful in condensing and disseminating applicable self-advocacy information to adults with disabilities and their caregivers. Maintenance assessment results show that participants reported gaining new knowledge, improving confidence in their decision making, enhancing their ability to make friends in new situations and to persist when something has gone wrong. Several adults with disabilities said that felt empowered to speak up for themselves in situations where they would have previously refrained, and assessment results corroborated these statements as participants overall psychological empowerment score increased by 15 percent between the pre- and maintenance assessments.

The number of participants who read about disability provider agencies more than doubled from the pre- to maintenance assessment, and caregivers said they felt more informed about social services near their homes. Despite these increases, adult levels of autonomy and self-realization did not change over time, and future self-advocacy trainings need to be adapted to each participant's learning style. Self-advocacy is multifaceted, and assessment results may indicate that a short-term training can be effective in building confidence, a sense of empowerment and individual relationship-building skills, but that it may take more time to change individual self-perceptions and independence, as well as change larger familial patterns.

ADDPC and Morrison Institute partnered again in 2017 to facilitate another self-advocacy training in an underserved community. Using lessons learned and best practices from the 2016 project, Morrison Institute staff hosted a two-day training seminar in Yuma, Arizona, on June 1-2. Self-advocacy training results from the second year of the study were released in October 2017.

End Notes

[1] Comprehensive Annual Review. 2016. Second Annual Report. Arizona State University and Arizona Developmental Disability Planning Council. https://addpc.az.gov/sites/default/files/media/Comprehensive%20review%20and%20analysis_2016%202nd%20Edition_0.pdf

[2] "Demographic profile of Hispanics in Arizona, 2014" Pew Research Center, Washington, D.C. http://www.pewresearch.org/about/use-policy/.

[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

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