

REPORT ON

SELF-ADVOCACY IN ARIZONA

Arizona Developmental Disabilities Planning Council – Survey to
Identify Groups

May 31, 2013





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BACKGROUND

Contract

The Arizona Developmental Disabilities Planning Council (ADDPC) and the Arizona Board of Regents for and on behalf of Northern Arizona University (NAU) and the Institute for Human Development-Arizona University Center on Disabilities (IHD-AzUCD) entered into Interagency Service Agreement (ISA) ADDPC-02-11-2012 on January 1, 2013. The ISA ends on May 31, 2013.


The purpose of the ISA was to support the ADDPC's Goal #1 "Build a self-advocacy alliance comprised of diverse advocacy organizations that is led by persons with developmental disabilities." The ISA's specific task was to develop and conduct a survey to identify Self-Advocacy (SA) groups in Arizona with an emphasis on local, statewide, and national groups in each Arizona County. The survey is to include information about the active membership, products, community partnerships, impact, structure and resources of identified SA groups in Arizona.

The State of Self-Advocacy in Arizona

Self-advocacy is an enigma. With its many varied definitions and derivations it is difficult to understand or explain. Ask any individual with a disability to share their definition of self-advocacy and you will get a particular and personalized answer. Query a parent about self-advocacy and one will be reminded of the protections, obstacles, and exclusive perspectives a family has experienced with service delivery systems, educational institutions, and societal intolerances that parallel having a child with a disability. Discuss self-advocacy with the many professionals or service providers that work with people with disabilities and find diverse dealings and steadfast suggestions to the development and trajectory of a person's life with a disability. Investigate the general population and witness aggressive attitudes and ill-informed contexts as to the meaningful and productive lives one can have with a disability. Self-advocates in Arizona find themselves in the middle of all these perspectives while attempting to create one for their own self-identity.

In assessing the state of self-advocacy in Arizona, there are some qualitative distinctions that are generally agreed upon in describing self-advocacy. First, self-advocacy is an integral and important part of the disability culture. Culture is the cumulative efforts and acclimations of a population to its environment and surroundings. When cultures share the same space, a transmission of beliefs and values can be shared and celebrated. It takes a collective determination to make it work.

Second, self-advocacy is part of a civil rights movement that intersects race, class, sex, religion, age, sexual orientation, and national origin. It is a practice to reduce the discrimination and oppression of



people with disabilities and equip them with the skillsets, experience, and knowledge necessary to take greater control of their lives. It gives them a voice and access to communicating with the people and the systems that provide them services. The movement's nascent underpinnings are spread across the state and in selective areas of the state.

Third, self-advocacy is an attitude. Attitude can be thought of as a set of beliefs, understandings, and personal values that are ready for rearranging and adjustment. It is how one carries oneself and is typically reflected in a person's behavior. It is how we evaluate our experiences and express our advocacy.

Self-advocacy is a complex combination of individual perspectives, cultural values, and social systems and before moving forward in the presentation of this data, there are some selected quotes from phone conversations to consider. The assortment of comments lends itself to the preceding qualitative distinctions and the difficulty in accepting and designing a common definition of self-advocacy. In the loose interpretation of the comments, one can see that an intelligent and comprehensive design to the ADDPC's Goal #1 to "Build a self-advocacy alliance comprised of diverse advocacy organizations that is led by persons with disabilities" will necessitate an involved, strategic set of activities.

“Self-advocacy is very fragmented in our state. It is certainly not unified. The meetings are inconsistent.”

“The term is murky. The message is the same every time in tone and delivery. It does not fluctuate or adjust to the environment.”

“Self-advocacy is an all-encompassing life style. Individuals with disabilities should be able to shift their performance and be encouraged to develop more sophisticated ways to communicate.”

“Many of these groups say they provide advocacy, but I don’t know if they are self-advocacy groups.”

“There is a conflict with provider agencies and self-advocates.”

“Younger parents with their children are getting self-advocacy more. It is great that educators are paying attention and understanding self-advocacy. It is slowly moving into hearts and minds.”

“We sure need help here.”

“I have had many conversations with parents interested in self-advocacy or support groups for kids with disabilities.”

“We used to have one. It took a lot of coordination, but we did it. We don’t feel like we have a stake in it anymore.”

“There is a huge void.”

“No matter what we are advocating for (education, transportation, employment), advocacy is huge.”

“There is no roadmap.”

METHODOLOGY

This report is based on polling conducted from February to May 2013 using surveys designed in SurveyMonkey, Inc. The surveys were sent to SA groups via an email link or offered in an over-the-phone option. The aim of the survey was to gather information about the SA groups' active membership, products, community partnerships, impact, structure and resources.

By collecting the information and compiling the data, IHD-AzUCD will provide the ADDPC a resource to further ADDPC's mission to work in partnership with individuals with disabilities and their families through systems change, advocacy and capacity building activities that promote independence, choice and the ability of all individuals to pursue their own interests. This report may serve as a resource to see where SA groups exist, to understand the state of SA groups in Arizona, and to act as reference to inform potential grantees on how to strengthen existing or newly formed SA groups. The information in this report was generated from the following methods:

Phases:

Phase 1: January 2013 – February 2013

- Develop and Finalize SA Survey
- Present and get approval for the survey from the ADDPC

Phase 2: February 2013 – April 2013

- Conduct the survey and collect data
- Compile and categorize the data for reporting purposes
- Present preliminary data to the ADDPC

Phase 3: May 2013

- Develop draft of the report for ADDPC feedback
- Present the final report to the ADDPC
- Close the project

Tools:

Survey Monkey, Inc., Palo Alto, CA www.surveymonkey.com

Emails- to provide a link to the survey

Telephone- to administer the survey and interview participants about self-advocacy

FINDINGS

The data set represented in these questions can be categorized in the following subsets for self-advocacy groups: active membership, products, community partnerships, impact, structure and resources. While reviewing the data, it is important to demarcate the groups into the subsequent distinctions:

- a group governed by self-advocates,
- self-advocate and family run groups,
- disability specific groups,
- groups associated with qualified vendors,
- disability organizations that have social groups that serve as support groups
- youth self-advocate groups.

Each type of group may cross-over in purpose but also have defining characteristics that influence the make-up of the group.

Variables that affected the data included non-response to provided email links and phone calls, confusion about the definition of self-advocacy, and the unfamiliarity with the groups in the participants' area.

One of the immediate findings for IHD-AzUCD was the low response rate for sending the survey via an email link. Respondents were limited to 5 before IHD-AzUCD made the adjustment to individually call contacts and offer an over-the-phone option of filling out the survey. In the end, the experience was beneficial for the administrator of the phone calls and the respondent. We believe that lasting connections were made in the one-on-one phone conversation with self-advocates, family members, and professionals in the field.

For your reference, the survey will be available for review and download in the appendices. Prior to addressing each individual question in the survey, the next page will provide a discussion the results and charts for the questions.

How to read the results:

There are two types of questions:

Type 1:

Arizona Self-Advocacy Group Identification

Does the group have an adviser trained in self advocacy?		
Answer Options	Response Percent	Response Count
Yes	88.2%	15
no	11.8%	2
<i>answered question</i>		17
<i>skipped question</i>		2

TYPE 1:
Respondents
select *one*
choice. The
RESPONSE
COUNT
equals 17.

Type 2:

Arizona Self-Advocacy Group Identification

How does the group share information between members?		
Answer Options	Response Percent	Response Count
Email	93.8%	15
Telephone	87.5%	14
Social media	37.5%	6
Newspaper	6.3%	1
Word of mouth	81.3%	13
Flyers	50.0%	8
Other (please specify)	50.0%	8
<i>answered question</i>		16
<i>skipped question</i>		3

TYPE 2:
Respondents
select *multiple*
choices. The
RESPONSE
COUNT
exceeds 17.

Other (please specify)

- at the meetings
- At the meetings.
- Texting
- text | web
- ABIL Newsletter SWI Newsletter
- webinars
- Newsletters
- Workshops and conferences.

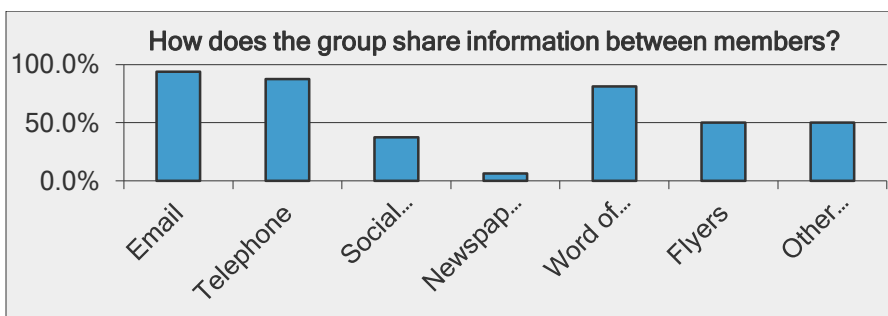


Chart to
display the
data

How to read the results:

List of icons: *Icons indicate the area of inquiry the question addresses*

-  Active Membership
 -  Products
 -  Community Partnerships
 -  Impact
 -  Structure
 -  Resources
-

The format of the findings section:

Question #:

Question Related to the Identification of SA Groups?

 **ICON**

Results:

Examination of the data collected

Question 1:

Arizona Self-Advocacy Group Identification

Please list any other self-advocacy groups in your area along with contact information if available. If there are no other groups in your area enter "N/A".

Response Count	
18	
No	Response Text
	Glendale version not associated with others - not a lot of communication between the group
1	AzAssist - East Valley and West Valley
2	Community Legal Services ALTEC WACOG NAMI Azpire Coconino County Coalition for Children and Youth FTF seen others in the
3	newspaper
4	People First YAC AZ
5	Hopi/Tewa Women's Coalition H.O.P.I. Substance Alliance Black Mesa Trust Sahuarita Parents of Exceptional Kids - SPEK Facebook page Only Parent Group Support meetings, mentorships, and trainings- educate in all aspects of disability and for the school numbers in powers to improve the district's ed program United Way - just started southern Arizona Family Support Service through United Way classes and trainings - early childhood trying to
6	collaborate with special olympics. AZ Assist: Autism Spectrum Support Information and Strategies for Transition Families and Young Adults with kids on the spectrum Family Support Group 501 c3 Monthly meeting Parents care givers professionals social environment for the youth. Additional Social event in the community Housing - Transition - Voc Rehab Professionals invited What we have seen happen, these teens and young adults that use their strength to help each other - teaching each to do all sorts I have 80 people a month show up for professional information only group like us in AZ
7	(greater metropolitan area). Completely unfunded
8	same as SABE list - see below SABE People First PF of Tucson Compass YAC AZ OASIS Art Gode - The Bobcats (Clint Gode) Currently working on 1 or 2 on the Navajo Nation - Kayenta (develop another in tuba city). NAG (10 years old) - Native American Group - Tuba City Voice - West/Glendale / Valley Janine Warner AZ Assist is a parent group - activities/support group Siblings network the ARC of the US NDRN UCEDD EAST Valley OASIS supported by the MARC Center - activity base YUMA -
9	The saguaro The ARC in Yuma - the transition group - family support
10	SAC of AZ People First of AZ OASIS - out of PHX AzDAC Compass ? YAC AZ SARRC National Federation if the Blind of AZ Arizona Council of the Blind OASIS- part of the ARC
11	AZDAC- I consider AZDAC as self-advoacy group ADDPC People First of AZ SAC of AZ People First of Tucson - Michael Pliska 520-272-3556 Arc of Tucson Southern Arizona Down
12	Syndrome Network
13	TASH at NAU Northern Arizona Autism Society of America
14	N/A
15	n/a NAMI AZ has 10 affiliates in various cities, areas & counties in AZ & have their own by-laws & individual non-profit TAX ID #'s. They are: NAMI AZ, NAMI Southern (Pima), NAMI (Cochise), NAMI (Pinal), NAMI Phoenix, West Valley, Mesa, NAMI Yuma (Yuma), NAMI Sedona
16	(Yavapai/Coconino) & NAMI Flagstaff (Coconino).
17	na
18	N/A

Question 1:

Please list any other **self-advocacy** groups in your area along with the contact information, if available. If there are no other groups in your area enter "N/A".

A

Our findings in relation to Questions #1 (Q1) are listed below:

Group Listed	Mentions	Self-Advocacy
Compass	3	Peer Support Group
Adults with Autism/Asperger's Support Group (Glendale)		Peer Support Group
Adults with Autism/Asperger's Support Group (Central)		Peer Support Group
Autism Spectrum Support Information and Strategies for Transition (AZ ASSIST-East Valley)	2	Support Group
Autism Spectrum Support Information and Strategies for Transition (AZ ASSIST-West Valley)	2	Support Group
Community Legal Services (CLSAZ)		Not-for-Profit Arizona Law firm
Arizona Long Term Care System (ALTCS)		Part of Arizona Health Care Cost Containment System (AHCCCS)
Western Arizona Council of Governments (WACOG)		Governmental Non-Profit
National Alliance on Mental Illness (NAMI) and Affiliates	2	National Non-Profit
Coconino County Coalition for Children and Youth		County Non-Profit
First Things First (FTF)		Early Childhood
People First of Arizona (PFAZ)	4	Self-Advocacy

Youth Action Council of AZ (YAC-AZ)	2	Self-Advocacy
Hopi/Tewa Women's Coalition		Social Advocacy Organization
H.O.P.I. Substance Abuse		Prevention Center
Black Mesa Trust		Non-Profit – HOPI Water Issues
Sahuarita Parents of Exceptional Kids (SPEK)		Support Group
Self-Advocates Becoming Empowered (SABE)		Self-Advocacy
People First of Tucson	2	Self-Advocacy
The Bobcats		Self-Advocacy
Native American Group (NAG)		?
Value of Implementing Consumer Empowerment (VOICE)		Disability Support, Education, Social, and Information Group
The ARC of the US		Disability Organization
National Disability Rights Network (NDRN)		National Protection and Advocacy
University Centers for Excellence in Developmental Disabilities (UCEDD)		DD Network
East Valley OASIS supported by the MARC Community Services	2	Disability Organization
The Saguaro		Disability Organization
The ARC in Yuma		Disability Organization
Self-Advocacy Coalition of Arizona (SAC of AZ)	2	Self-Advocacy
Arizona Disability Advocacy Coalition (AZDAC)	2	Disability Advocacy Group
The Southwest Autism Research & Resource Center (SARRC)		Research and Outreach Group
National Federation of the Blind of Arizona (NFBArizona)		Self-Advocacy/Advocacy
Arizona Council for the		Self-

Blind (AzCB)		Advocacy/Advocacy
Arizona Developmental Disabilities Planning Council (ADDPC)		DD Network
ARC of Tucson		Disability Organization
Southern Arizona Network for Down Syndrome (SANDS)		Disability Advocacy Group
TASH at NAU		Self-Advocacy
Northern Arizona Autism Society of America (NAzASA)		Disability Advocacy Group

Results:

The primary purpose of this question was twofold: it allowed the respondent to list the self-advocacy groups available to them in their area and it provided IHD-AzUCD with a list of self-advocacy groups that operated within the respondent's proximity. The question clearly stated to list **Self-Advocacy** groups, but the data collected resulted in a myriad of groups that were disability related. Many of these groups most likely have components of self-advocacy built into their programs. From the perspective of a group that is purely run by self-advocates, there were 6 that qualified.

Question 2:

Arizona Self-Advocacy Group Identification

At what regional level does the group operate?

Answer Options	Response Percent	Response Count
Local	52.9%	9
County	29.4%	5
State	17.6%	3
National	0.0%	0
Multinational	0.0%	0
Other (please specify)		5
	<i>answered question</i>	17
	<i>skipped question</i>	2

Other (please specify)

the area around PHX and suburbs

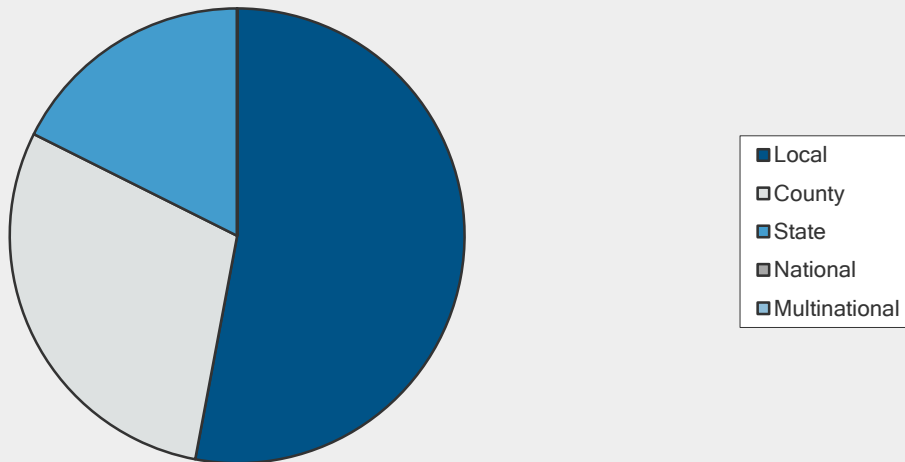
all of Yuma County

local | County | Interact Statewide - similar org in Tucson | part of statewide task force

Local | County | Try to do State-wide with a conference

families that come from Surprise | Mesa | Gilbert | and a family from Flagstaff

At what regional level does the group operate?



Question 2:

At what regional level does the group operate?



Results:

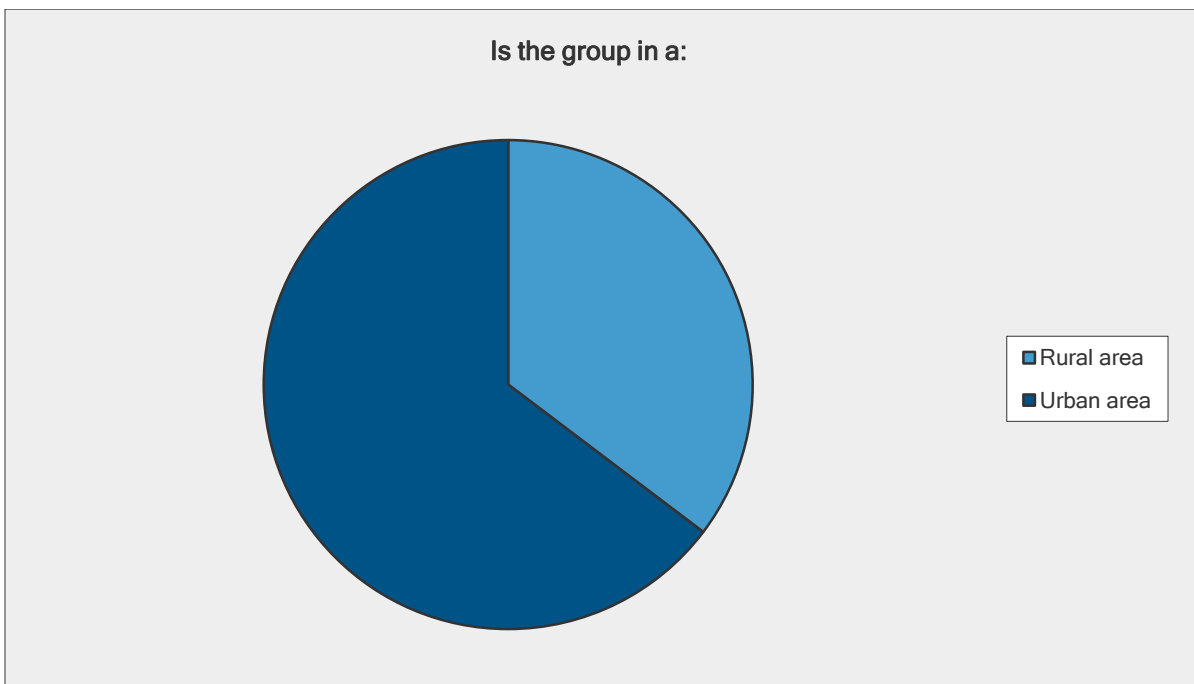
Of the 17 Respondent's groups, 52.9% of groups operated at **Local** levels, 29.4% at **County** levels, and 17.6% at the **State** level while 5 answered that they operate at more than one level. In the comments section labeled as **Other (please specify)**, groups indicated the levels at which they operate. Although some groups did not operate state-wide, the groups were part of task forces, put on conferences, or interacted state-wide.

Question 3:

Arizona Self-Advocacy Group Identification

Is the group in a:		
Answer Options	Response Percent	Response Count
Rural area	35.3%	6
Urban area	64.7%	11
Other (please specify)		2
<i>answered question</i>		17
<i>skipped question</i>		2

Other (please specify)
both
both - outlying parts that rural



Question 3:

Is the group in a:

Results

The data showed that of the respondent's groups, 6 were located in **Rural** areas, 11 located in **Urban** areas, and of the 17 there were 2 that operated in both **Rural** and **Urban** areas. While the majority that responded operated in **Urban** areas, the **Rural** representation came at over 1/3 of the groups.

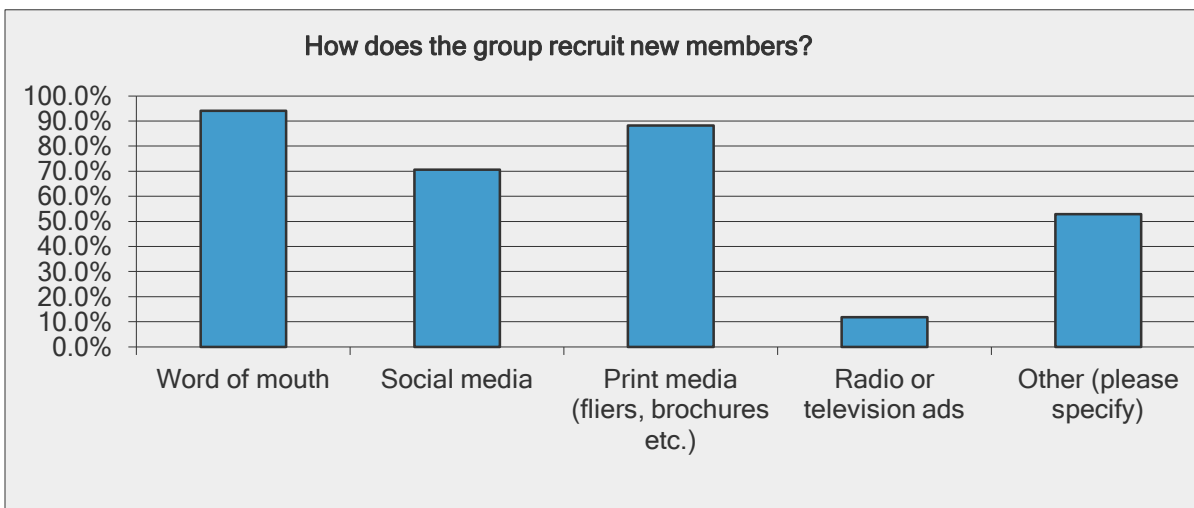
Question 4:

Arizona Self-Advocacy Group Identification

How does the group recruit new members?		
Answer Options	Response Percent	Response Count
Word of mouth	94.1%	16
Social media	70.6%	12
Print media (fliers, brochures etc.)	88.2%	15
Radio or television ads	11.8%	2
Other (please specify)	52.9%	9
<i>answered question</i>		17
<i>skipped question</i>		2

Other (please specify)

web sites || autism advocacy orgs - Autism Society of America || Meet up site for people who already know us
 newspaper- Yuma Daily Sun
 public speaking | presentations
 Pilot Parents of Southern AZ - referrals
 vendor tables | transition fairs
 conferences, transition fairs,
 website
 currently not active | we have not had an election in 3 years (2009) - right after becoming a non-profit
 Questions #1 & #2 correctly should be that we operate Locally, County, State & National levels as well as in Rural & Urban areas We are also operating on Native American Reservations.



Question 4:

How does the group recruit new members?

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I

Results:

The data revealed that groups primarily use **Word of Mouth, Print Media, and Social Media** to recruit new members. In the comments section labeled as **Other (please specify)**, the respondents listed events at which recruitment takes place. Types of events included Meet-ups, conferences, transition fairs, and presentations.

Question 5:

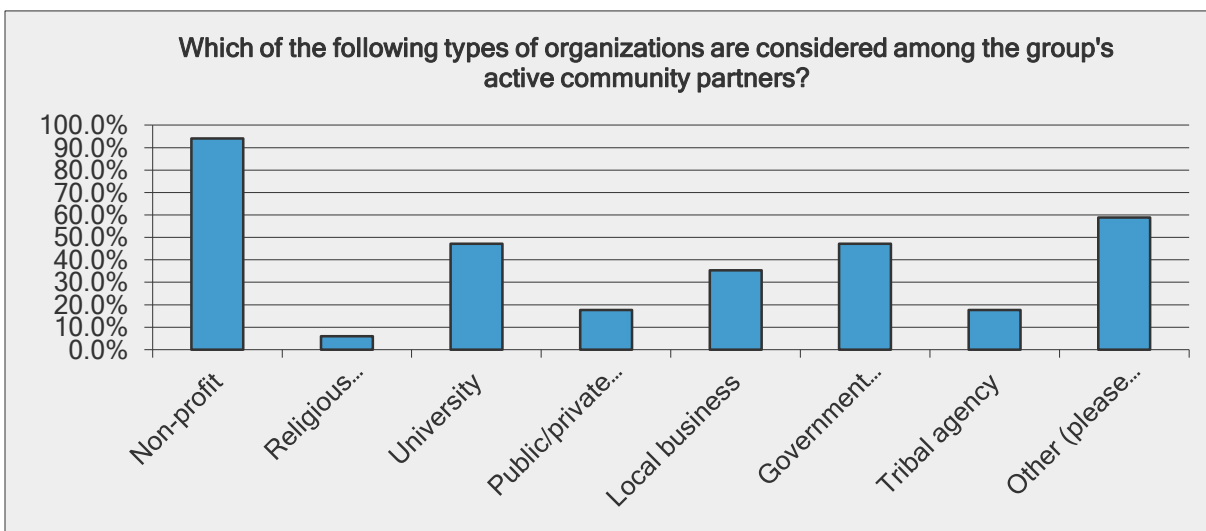
Arizona Self-Advocacy Group Identification

Which of the following types of organizations are considered among the group's active community partners?

Answer Options	Response Percent	Response Count
Non-profit	94.1%	16
Religious organization	5.9%	1
University	47.1%	8
Public/private school	17.6%	3
Local business	35.3%	6
Government agency	47.1%	8
Tribal agency	17.6%	3
Other (please specify)	58.8%	10
	<i>answered question</i>	17
	<i>skipped question</i>	2

Other (please specify)

Coordinate some times with a professor at ASU || Small training program through VR at one time, but the funding was cut. funding from HUD
 Counseling groups as businesses ||
 American Legion | PRIVATE - Christ Church Lutheran helps with fundraising
 parent partners of United Way - collaboration / effectiveness | what things needed in the community | shopping carts and accessible playgrounds |
 OCSHCN | families from tribal communities | professionals from ADE and Disability Resource Centers on Universities | WIN work group | PROMISE work group
 Dept of Education - AZ
 potentially NASCAR | NIDRR- in talks | Legislators | National Disability Council - provides administrations on issues | NCIL - Hopi Nation | Navajo Nation
 People with ABIL-Affiliations - Part of our group and supportive |
 Arizona Foundation for the Handicap - Private Agency



Question 5:

Which of the following types of organizations are considered among the group's active community partners?

CP

Results:

The data showed that of the respondent's groups, all but one have a community partnership with a **Non-profit. Universities** and **Government Agencies** were shown to work with close to half of the respondent's groups. **Local businesses** have a stake in the operations of the respondent's groups coming in at 35.3%. In the comments section labeled as **Other (please specify)**, specific groups were mentioned.

Question 6:

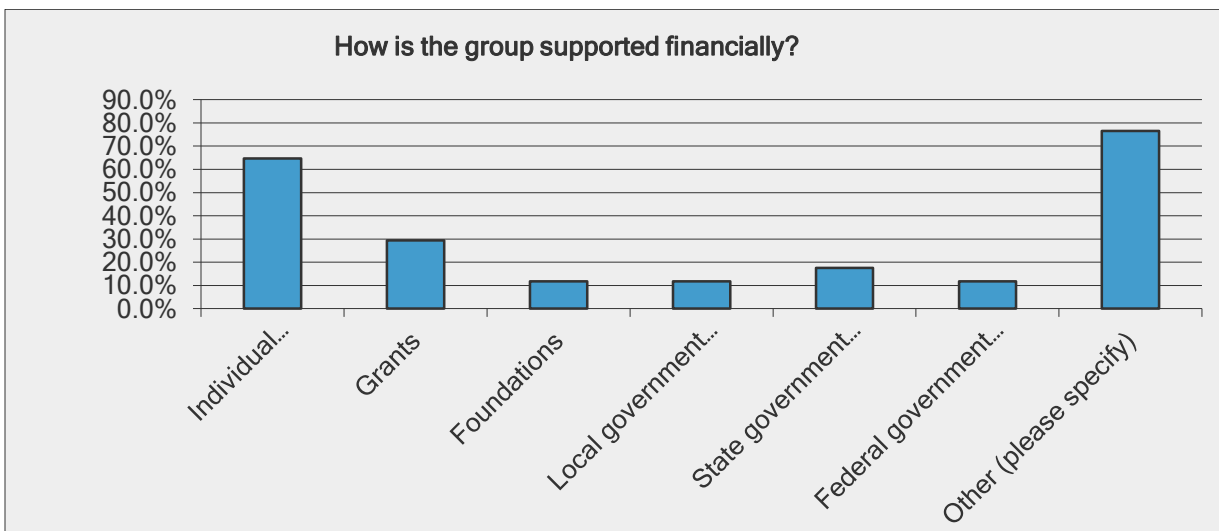
Arizona Self-Advocacy Group Identification

How is the group supported financially?

Answer Options	Response Percent	Response Count
Individual contributions	64.7%	11
Grants	29.4%	5
Foundations	11.8%	2
Local government funding	11.8%	2
State government funding	17.6%	3
Federal government gunding	11.8%	2
Other (please specify)	76.5%	13
<i>answered question</i>		17
<i>skipped question</i>		2

Other (please specify)

small stipend from Autism Society of America for meetings through SMILE
 United Way Funding through United Way and the City ||
 Fund Raisers | Bake Sales | Dances
 fundraising with food sales, footrace, and raffle
 No finances right now other than individual | food and flyers
 Fundraising
 Donations / non-profits (meeting spaces) | ADDPC
 AIDD | Membership Fees | Disability Policy Summit - get money from being a partner
 Not that i know of
 memberships
 support from nonprofits
 By other non profit organizations.



Question 6:

How is the group supported financially?

S

Results:

Individual contributions made for the majority in the category of financial support. **Grants** supported 29.4% of the groups. In the comments section labeled as **Other (please specify)**, other categories were mentioned including stipends, organizational support, membership fees, donations, and fundraising.

Question 7:

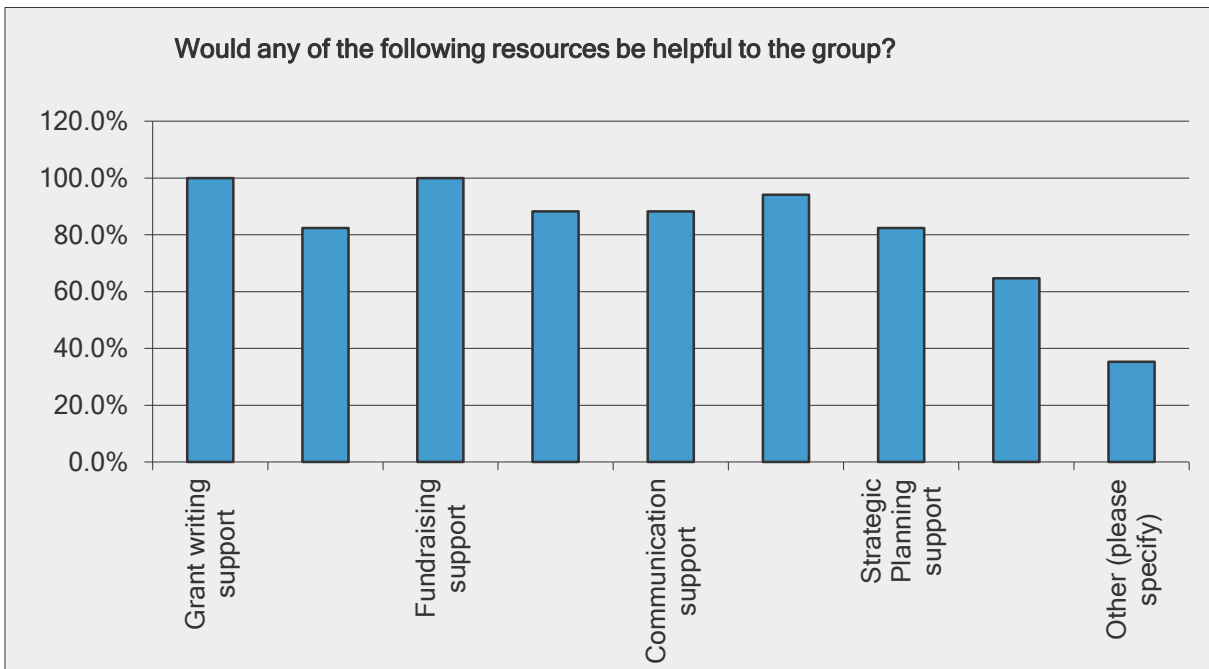
Arizona Self-Advocacy Group Identification

Would any of the following resources be helpful to the group?

Answer Options	Response Percent	Response Count
Grant writing support	100.0%	17
Foundation request support	82.4%	14
Fundraising support	100.0%	17
Marketing support	88.2%	15
Communication support	88.2%	15
Leadership development/ training	94.1%	16
Strategic Planning support	82.4%	14
Development of group structure including: visioning,	64.7%	11
Other (please specify)	35.3%	6
<i>answered question</i>		17
<i>skipped question</i>		2

Other (please specify)

more funding
 Help with Social Media | SPEAK project helping with mission/vision
 working with United Way for the shopping carts |
 Board Training and Board Development - took classes at TAP | Dvlp director from the TCH |
 recruitment and retention | community partnerships
 recruitment and retention



Question 7:

Would any of the following resources be helpful to the group?

R

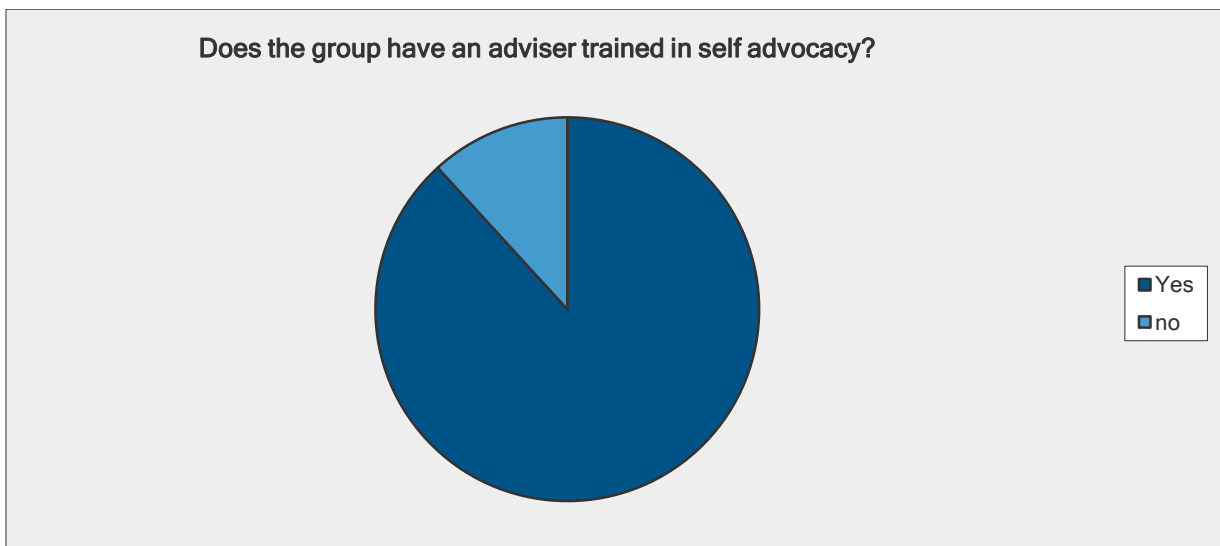
Results:

Of all the answer options, only one fell below an 80% response rate- **Development of group structure including visioning, guiding principles, mission statement, purpose, goals, etc.** It is clear that all of the respondent's groups would participate in training surrounding **Grant writing support, Foundation request support, Fundraising, Marketing, Communication support, Leadership development/training, and Strategic planning.** Of the 8 answer options, **Grant writing support** and **Fundraising support** were listed at 100%. In the comments section labeled as **Other (please specify)**, other types of training were mentioned: recruitment and retention and community partnerships.

Question 8:

Arizona Self-Advocacy Group Identification

Does the group have an adviser trained in self advocacy?		
Answer Options	Response Percent	Response Count
Yes	88.2%	15
no	11.8%	2
<i>answered question</i>		17
<i>skipped question</i>		2



Question 8:

Does the group have an adviser trained in self-advocacy?



Results:

The data showed that 88.2% of the groups had an adviser trained in self-advocacy. While most of the groups had an adviser trained in self-advocacy, 2 self-identified self-advocacy groups did not have an adviser trained in self-advocacy.

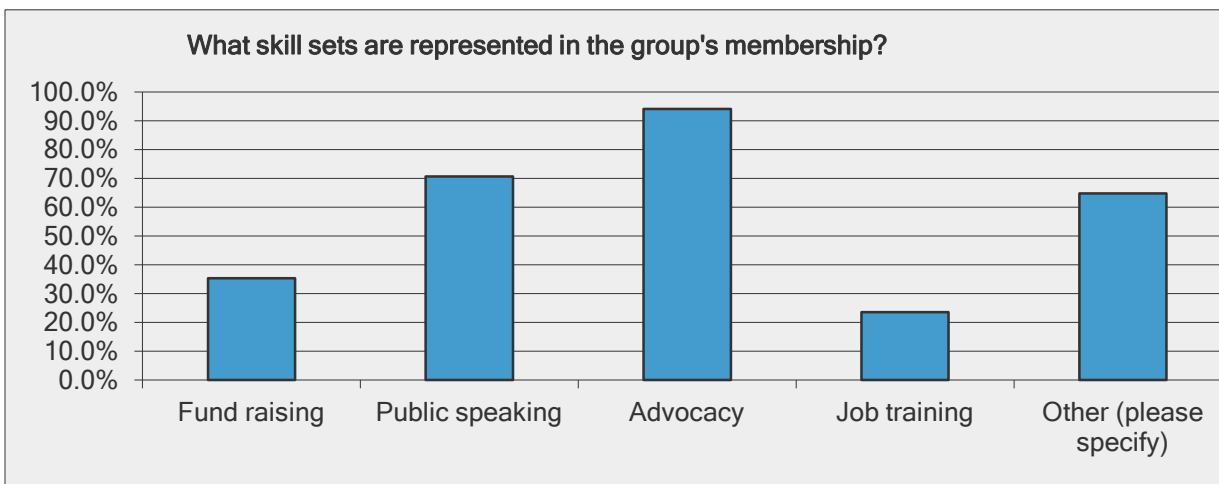
Question 9:

Arizona Self-Advocacy Group Identification

What skill sets are represented in the group's membership?		
Answer Options	Response Percent	Response Count
Fund raising	35.3%	6
Public speaking	70.6%	12
Advocacy	94.1%	16
Job training	23.5%	4
Other (please specify)	64.7%	11
	<i>answered question</i>	17
	<i>skipped question</i>	2

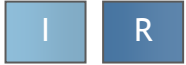
Other (please specify)

Computer Technicians ||
 sort of fund raising, sort of grant writing,
 Focus is Self-Advocacy | We have learned to put on
 Conferences - Aug/Sept 2014 - next date
 note: membership fluctuations | interested in any sort of job
 training (personal)
 In the community of my parent group - there are trainers who
 understand employment
 mentorship program
 Community Partnerships | Legislative
 grant writing | how to use the grant money- how do you spend
 your money | board member training
 Educators of younger self-advocates to be self-advocates. | We
 are a group of PWD mapping out our own plan of SA.
 Speaking for ourselves.
 none
 (EARS) Education, Advocacy, Research, & Support for the
 mentally ill & their families



Question 9:

What skill sets are represented in the group's membership?



Results:

The data revealed that members were mostly trained in Advocacy (94.1%) and Public speaking (70.6%). Supporting the 100% response rate for Question 7-**Fundraising support**, only 35.3% of the respondent's membership were trained in fundraising. In the comments section labeled as **Other (please specify)**, other skillsets included: computer technicians grant writing, conference organizing, mentorship, and education. An interesting comment made was that there should be a group of people with disabilities mapping out our own plan for self-advocacy.

Question 10:

Arizona Self-Advocacy Group Identification

What products and resources does the group provide?		
Answer Options	Response Percent	Response Count
Academic course development	5.9%	1
Conference presentations and posters presented	64.7%	11
Distance learning modules	17.6%	3
Electronic products	29.4%	5
Newsletters	41.2%	7
Pamphlets	58.8%	10
Brochures	76.5%	13
Fact sheets	52.9%	9
Press communications	23.5%	4
Reports and monographs	17.6%	3
Web-based products	23.5%	4
Peer mentoring program	47.1%	8
Community training	52.9%	9
Technical assistance	35.3%	6
Direct clinical services	5.9%	1
Demonstration services	0.0%	0
Performing research or evaluation	17.6%	3
Information distribution	11.8%	2
Web-site	41.2%	7
Facebook page	35.3%	6
Google+ page	5.9%	1
Twitter	0.0%	0
YouTube	17.6%	3
Blog	0.0%	0
List-serve	47.1%	8
Webinar	5.9%	1
Video conferencing	5.9%	1
Online research library	11.8%	2
Other (please specify)	58.8%	10
	<i>answered question</i>	17
	<i>skipped question</i>	2

Other (please specify)

partner with professors about research
 I do a lot of the work. Most things through SMILE
 working on clinical services | our goal is to have a clinic | would like to do
 research and evaluations | on our web-site we have additional resources
 and links
 Some Evaluation during conference | Have done a YouTube video in the
 past | on SABE listserv |
 Have been asked to be a peer advocate for IEP meetings |
 Radio interview soon
 Project Vote
 Tried several times with new letters- the editor has to do all the work. You
 have to have contributors. | We have had pamphlets. | We as officers report
 to general membership. Report to AzDAC for People First and vice versa. |
 We have gone all over the state with community training. | Emails | I do not
 know about social media. | We have done video conferencing.
 People First of Tucson's mission is to make sure all people with disabilities
 get the services they need by providing education and advocacy.
 support group

Question 10:

What products and resources does the group provide?

P

Results:

Only one product or resource listed at over 70%- **Brochures**. The outreach to the community was listed as: **Conference presentations and posters** at 64.7% and **Community training** at 52.9%. In the comments section labeled as **Other (please specify)**, respondents listed potentials of products and resources or difficulties with past products and resources.

Question 11:

Arizona Self-Advocacy Group Identification

From where does the group obtain products and resources?		
Answer Options	Response Percent	Response Count
Internet	76.5%	13
Educational organization	58.8%	10
Businesses	17.6%	3
School	17.6%	3
Non-profit organization	100.0%	17
Other (please specify)	58.8%	10
<i>answered question</i>		17
<i>skipped question</i>		2

Other (please specify)

word of mouth

Governmental resources | national non-profits

Trainings come from ABIL, SPEAK,

Tribal agency, state agency,

PINS | PARTNERS in Policy Making |

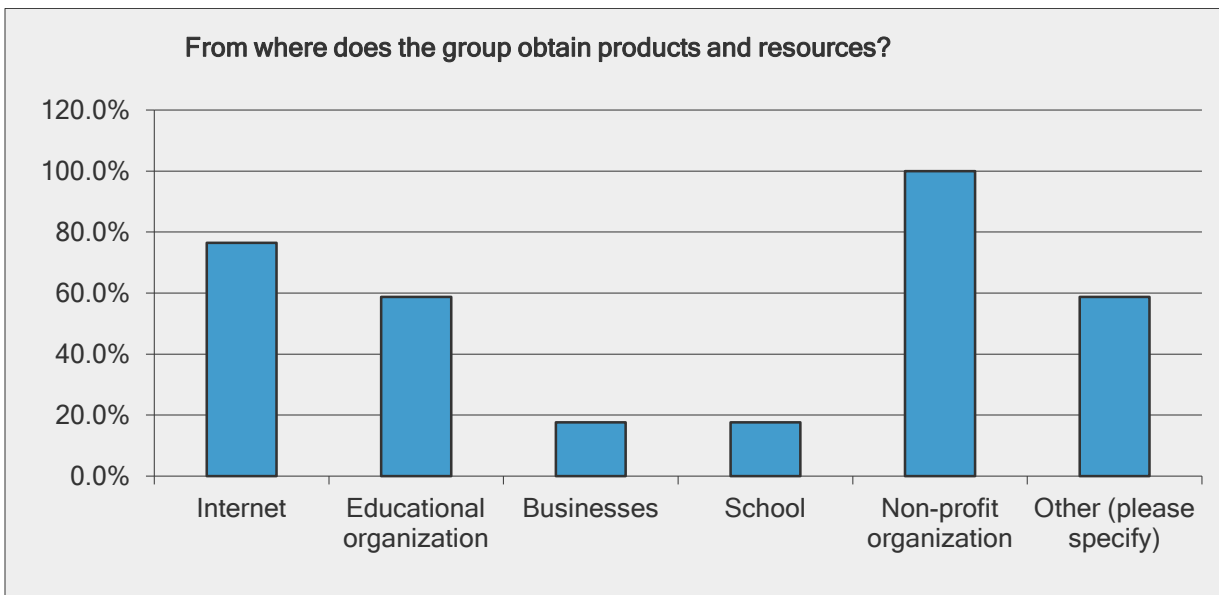
Conferences

state gov | donations

Gain knowledge from each other.

individuals

Local bussiness.



Question 11:

From where does the group obtain products and resources?

I

S

Results:

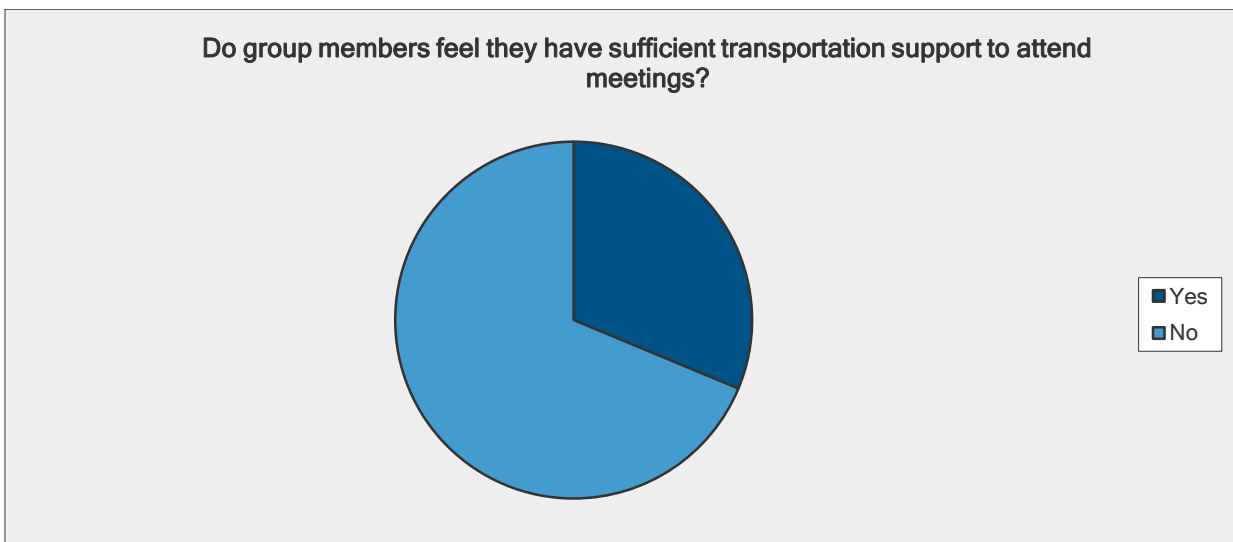
Products and resources were mainly obtained from **Non-profits** (100%), the **Internet** (76.5%), and **Educational organizations** (58.8%). In the comments section labeled as **Other (please specify)**, other state agencies and organizations were listed such as ABIL, SPEAK, PINS, and Partners in Policymaking. Conferences, local businesses, and information obtained from the constituents of the group rounded out the rest of the comments.

Question 12:

Arizona Self-Advocacy Group Identification

Do group members feel they have sufficient transportation support to attend meetings?

Answer Options	Response Percent	Response Count
Yes	31.3%	5
No	68.8%	11
	<i>answered question</i>	16
	<i>skipped question</i>	3



Question 12:

Do group members feel they have sufficient transportation support to attend meetings?

R

Results:

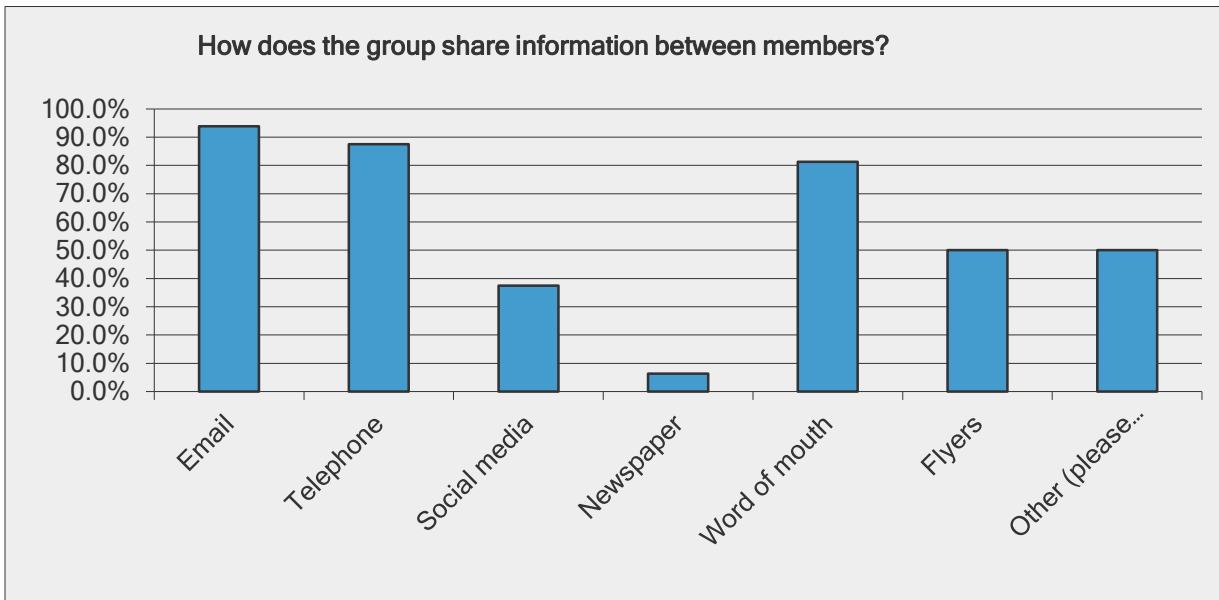
In response to sufficient transportation to attend meetings, 68.8% of the respondents said that they did not have sufficient transportation.

Question 13:

Arizona Self-Advocacy Group Identification

How does the group share information between members?		
Answer Options	Response Percent	Response Count
Email	93.8%	15
Telephone	87.5%	14
Social media	37.5%	6
Newspaper	6.3%	1
Word of mouth	81.3%	13
Flyers	50.0%	8
Other (please specify)	50.0%	8
<i>answered question</i>		16
<i>skipped question</i>		3

Other (please specify)
 at the meetings
 At the meetings.
 Texting
 text | web
 ABIL Newsletter SWI Newsletter
 webinars
 Newsletters
 Workshops and conferences.



Question 13:

How does the group share information between members?

A

I

S

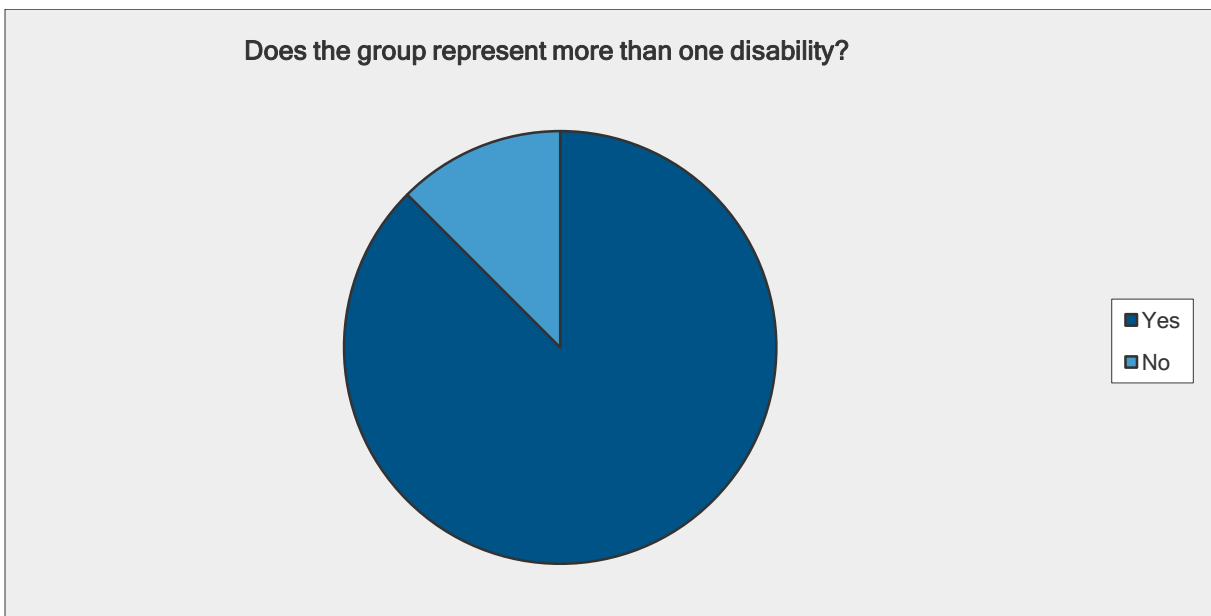
Results:

Email (93.8%), Telephone (87.5%), and Word of Mouth (81.3%) were the top three ways that the respondent's group members shared information with each other. In the comments section labeled as **Other (please specify)**, meetings, workshops, newsletters, texting, and meetings were listed as ways to share information.

Question 14:

Arizona Self-Advocacy Group Identification

Does the group represent more than one disability?		
Answer Options	Response Percent	Response Count
Yes	87.5%	14
No	12.5%	2
<i>answered question</i>		16
<i>skipped question</i>		3



Question 14:

Does the group represent more than one disability?



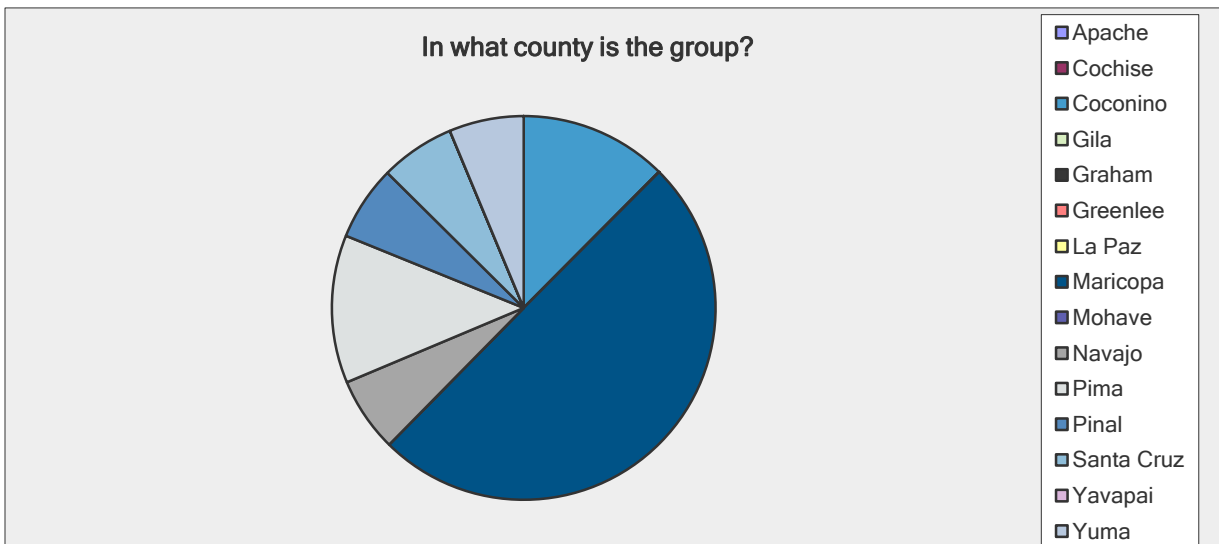
Results:

At 87.5%, the respondent's groups represented more than one disability.

Question 15:

Arizona Self-Advocacy Group Identification

In what county is the group?		
Answer Options	Response Percent	Response Count
Apache	0.0%	0
Cochise	0.0%	0
Coconino	12.5%	2
Gila	0.0%	0
Graham	0.0%	0
Greenlee	0.0%	0
La Paz	0.0%	0
Maricopa	50.0%	8
Mohave	0.0%	0
Navajo	6.3%	1
Pima	12.5%	2
Pinal	6.3%	1
Santa Cruz	6.3%	1
Yavapai	0.0%	0
Yuma	6.3%	1
Other (please specify)		0
<i>answered question</i>		16
<i>skipped question</i>		3



Question 15:

In what county is the group?

I

S

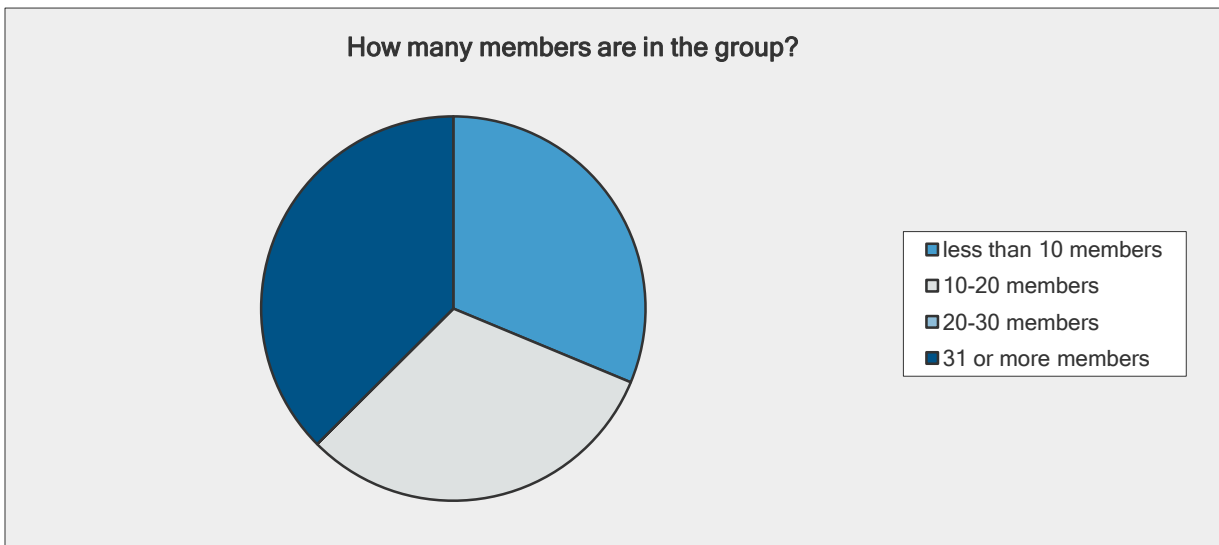
Results:

Of the respondent's groups, 50% were located in Maricopa County. There were 8 counties at zero percent participation for the survey.

Question 16:

Arizona Self-Advocacy Group Identification

How many members are in the group?		
Answer Options	Response Percent	Response Count
less than 10 members	31.3%	5
10-20 members	31.3%	5
20-30 members	0.0%	0
31 or more members	37.5%	6
<i>answered question</i>		16
<i>skipped question</i>		3



Question 16:

How many members are in the group?



Results:

The data showed membership levels at the following percentages:

- Less than 10 members - 31.3%
- 10-20 members- 31.3%
- 20- 30 members- 0%
- 31 or more members- 37.5%

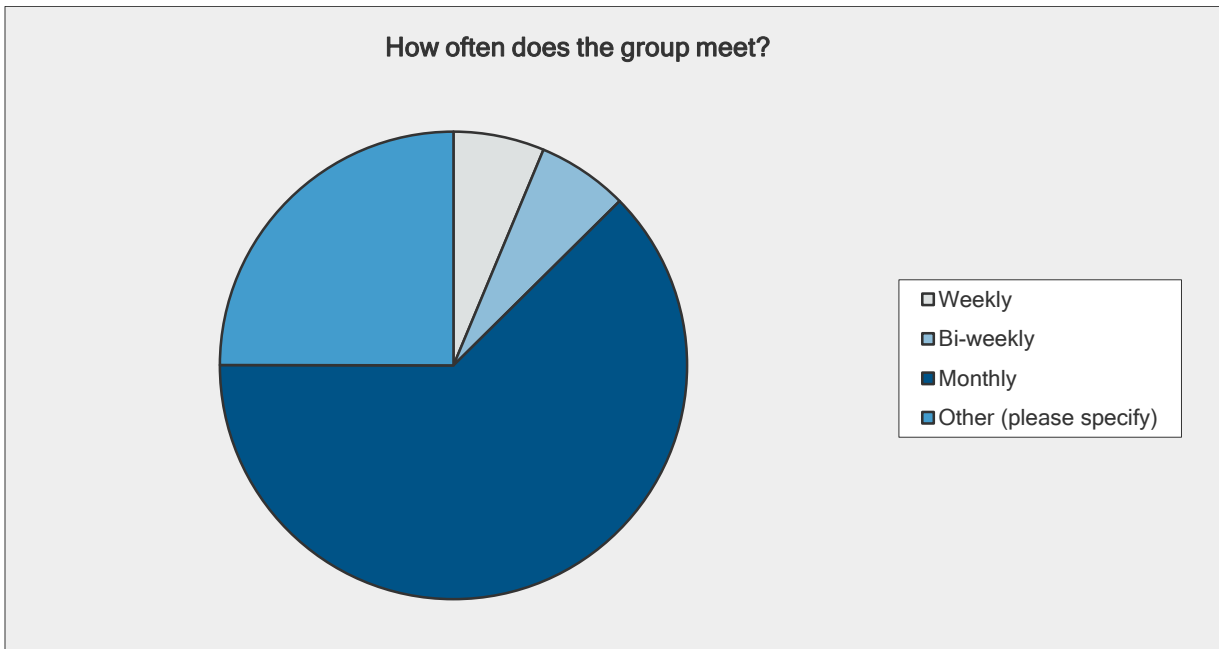
Question 17:

Arizona Self-Advocacy Group Identification

How often does the group meet?		
Answer Options	Response Percent	Response Count
Weekly	6.3%	1
Bi-weekly	6.3%	1
Monthly	62.5%	10
Other (please specify)	25.0%	4
<i>answered question</i>		16
<i>skipped question</i>		3

Other (please specify)

from September to May- depending on the heat - once a month
 We were holding monthly support meetings and will stop until more public education - for now re-evaluating. Focusing a lot this year on outreach to service providers, teachers, school counselors, social service providers, county healthy families. Training at juvenile probation.
 quarterly
 quarterly



Question 17:

How often does the group meet?

A	I	S
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Results:

The data showed the frequency of meetings at the following schedules:

- **Weekly- 6.3%**
- **Bi-weekly- 6.3%**
- **Monthly- 62.5%**
- **Other- 25%**

In the comments section labeled as **Other (please specify)**, some groups met quarterly and another group scheduled meetings during the more cooler times of the year.

Question 18:

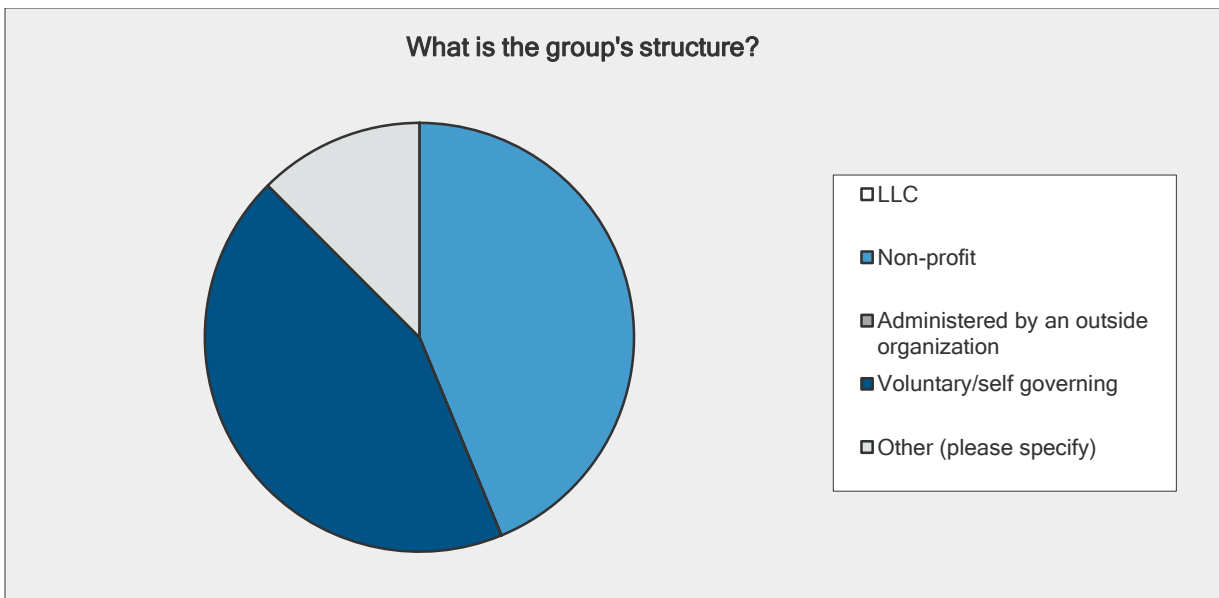
Arizona Self-Advocacy Group Identification

What is the group's structure?		
Answer Options	Response Percent	Response Count
LLC	0.0%	0
Non-profit	43.8%	7
Administered by an outside organization	0.0%	0
Voluntary/self governing	43.8%	7
Other (please specify)	12.5%	2
<i>answered question</i>		16
<i>skipped question</i>		3

Other (please specify)

501 (c) 3 corporation

A local branch of a national organization



Question 18:

What is the group's structure?

S

Results:

Both **Voluntary/Self governing** and **Non-profit** groups represented 43.8% of the respondent's group structure. In the comments section labeled as **Other (please specify)**, another non-profit selection and a designation of a local branch of a national organization were listed as structures.

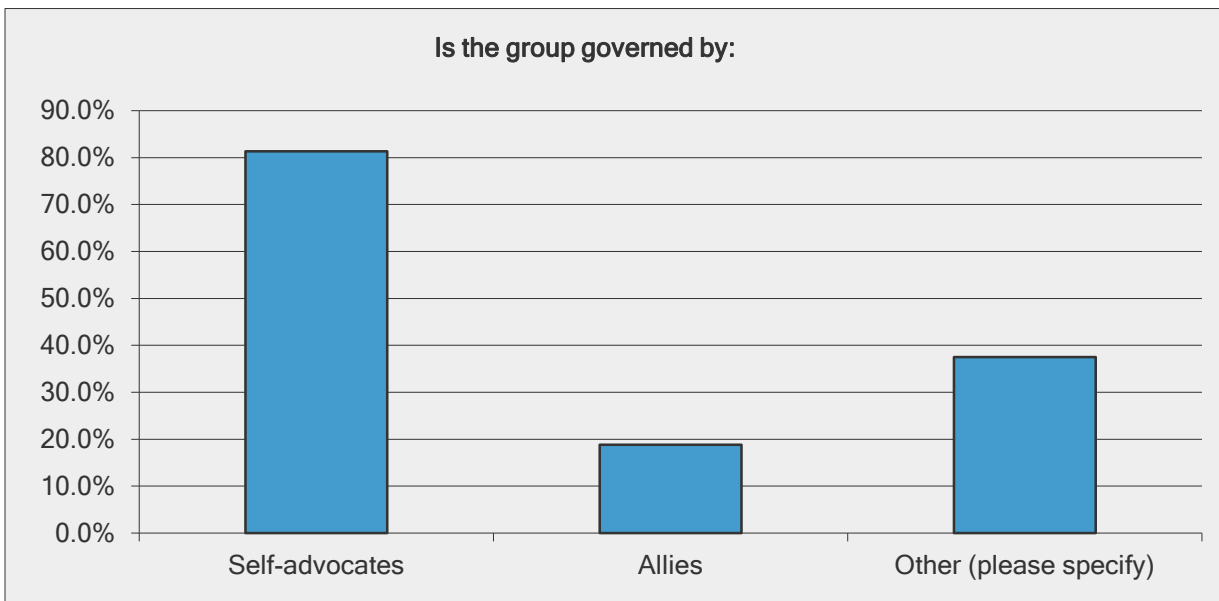
Question 19:

Arizona Self-Advocacy Group Identification

Is the group governed by:		
Answer Options	Response Percent	Response Count
Self-advocates	81.3%	13
Allies	18.8%	3
Other (please specify)	37.5%	6
<i>answered question</i>		16
<i>skipped question</i>		3

Other (please specify)

mild coordination from Autism Society of America (ASA)
governed by ourselves | advisory board in process | working on structure
both
appointed members
BOD
Almost totally PWD- cross section



Question 19:

Is the group governed by:

<input checked="" type="checkbox"/> A	<input type="checkbox"/> I	<input type="checkbox"/> S
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Results:

The data showed that 81.3% of the respondent's groups were governed by **Self-Advocates** while 18.8% were governed by **Allies**. In the comments section labeled as **Other (please specify)**, respondent's groups were also governed by: mild coordination from the host group, advisory boards, appointed members, cross sections, and a board of directors.

Question 20:

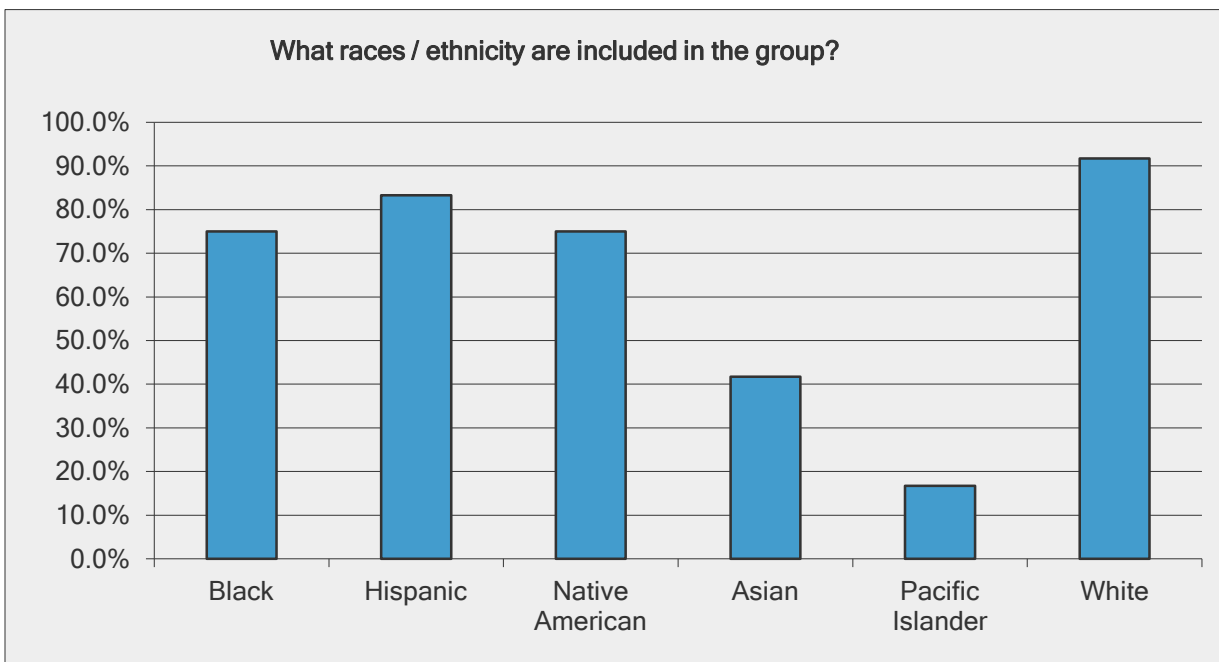
Arizona Self-Advocacy Group Identification

What races / ethnicity are included in the group?

Answer Options	Response Percent	Response Count
Black	75.0%	9
Hispanic	83.3%	10
Native American	75.0%	9
Asian	41.7%	5
Pacific Islander	16.7%	2
White	91.7%	11
Other (please specify)		6
<i>answered question</i>		12
<i>skipped question</i>		7

Other (please specify)

nobody is excluded - regardless of disability
 nobody is excluded
 nobody is excluded
 nobody is excluded
 not exclude
 all willing to attend



Question 20:

What races/ethnicities are included in the group?

A

I

S

Results:

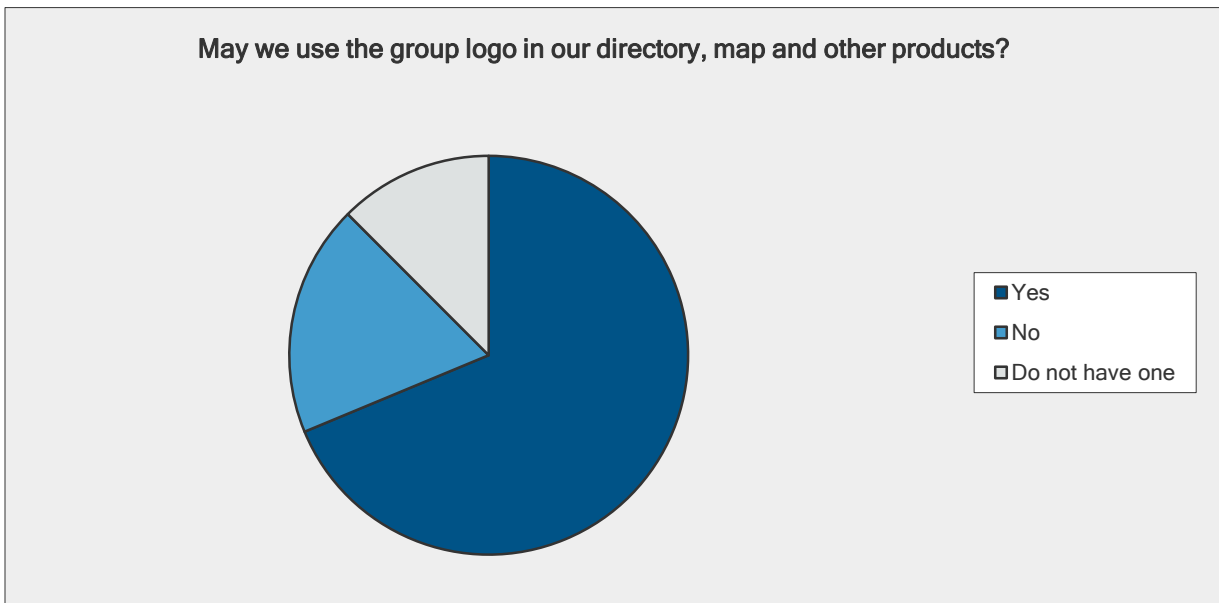
The racial designations of **Black**, **Hispanic**, **Native American**, and **White** were represented at over 70% in each of the groups. Asian and Pacific Islander both came in below 50%. In the comments section labeled as **Other (please specify)**, respondent's stated that all would be excepted if willing to attend.

Question 21:

Arizona Self-Advocacy Group Identification

May we use the group logo in our directory, map and other products?

Answer Options	Response Percent	Response Count
Yes	68.8%	11
No	18.8%	3
Do not have one	12.5%	2
<i>answered question</i>		16
<i>skipped question</i>		3



Question 21:

May we use the group logo in our directory, map, and other products?

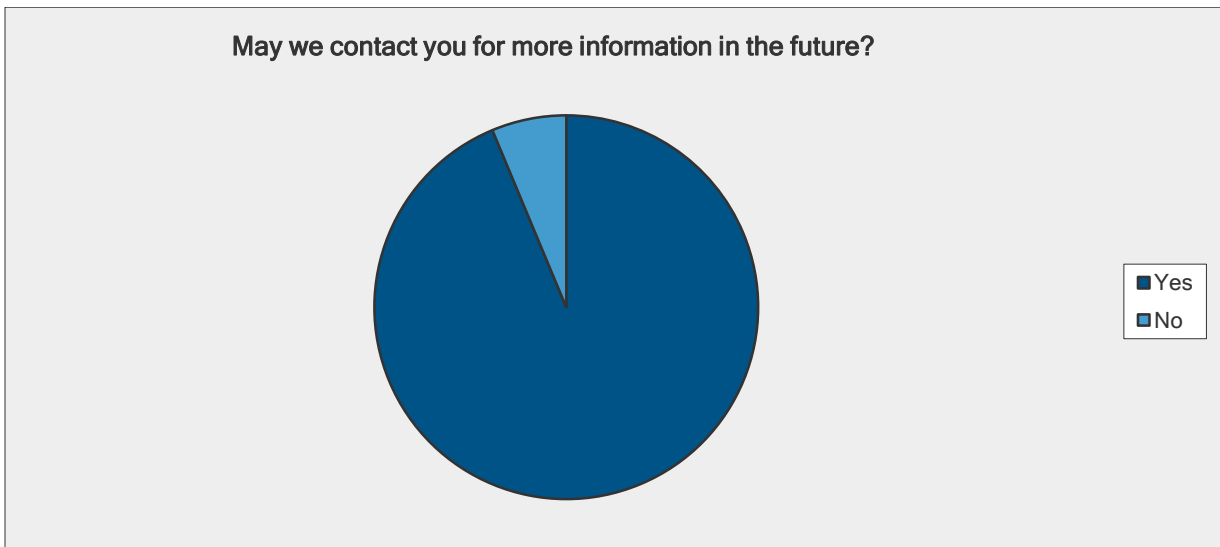


Question 22:

Arizona Self-Advocacy Group Identification

May we contact you for more information in the future?

Answer Options	Response Percent	Response Count
Yes	93.8%	15
No	6.3%	1
	<i>answered question</i>	16
	<i>skipped question</i>	3



Question 22:

May we contact you for more information in the future?



Question 23:

Arizona Self-Advocacy Group Identification

Demographic Information

Name	Group name:	Role	Representative's email address:	Phone number:
Tara Marshall	Adults Autism/Aspergers Support Group	Co-Cat Herder	azautisticadvocate@hotmail.com	602-421-2215
Shawnnita Miranda	The Lost Peepers	Advisor	shawnnita@smile-az.org	928-329-6681
Jean Richmond-Bowman	Fetal Alcohol Spectrum Disorder of Northern Arizona (FASDNA)	Creator / President	jrbowman@fasdna.org	928-853-2688
Nancy Tobey	OASIS - Arizona	Advisor	nancyt@azafh.com	602-956-0400
Veronica James	Pa'angwan Tota "Empowering Ourselves, Helping Others" Hopi Disability Advocacy	Secretary	vlj4@yahoo.com	928-401-9898
Mary Ann Scott	SPEK	Representative	scott.marianne@gmail.com	520-343-1507
Debbie Weidinger	AZAssist	Executive Director	debbie.weidinger@azassist.com	480-779-0899
George Garcia	Youth Action Council of Arizona (YAC-AZ)	Advisor/Facilitator	g.garcia@swifamilies.org	480-222-8800
Juliana Huerena	SABE	National Advisor	prinzjana@aol.com	x301 602 502 7426
Monica Cooper	Self Advocacy Coalition of AZ	President	monicacooperofaz@hotmail.com	602-315-4962
Bob Hickman	People First of Arizona Part of SABE	Representative	bobhofaz@centurylink.net	602-336-3020
Shannon Bergman	People First of Tucson	Advisor	shannonb@directilc.org	520-561-8772
Jennifer Kurth	TASH at NAU	Faculty advisor	jennifer.kurth@nau.edu	928-523-7125
Robin Weber	NAMI Pinal Central	President	grandmom.robin@yahoo.com	520-876-4124
NAMI AZ & NAMI YC	NAMI AZ & NAMI YC	President	jimdunn@namiaz.org	602-244-8166
Maria Scholnick	The Santa Cruz Parent Love Connection	Coordinator/Organizer	mariascholnick@yahoo.com	520-285-6112

Question 23:

Demographic Information



RECOMMENDATIONS

The **Self-Advocacy in Arizona-Survey to Identify Groups** report compiled data from nineteen groups in the state of Arizona. IHD-AzUCD examined the groups with survey by the following metrics: Active Membership, Products, Community Partnerships, Impact, Structure, and Resources. The data obtained outlined an overall snapshot of the self-identified self-advocacy groups in Arizona. In analysis of the data, there were some evident indications that the ADDPC should be aware of concerning self-advocacy groups in Arizona.

1. What constitutes a self-advocacy group is a source of confusion and debate. Respondents (self-advocacy group representatives) were asked to list self-advocacy groups in their area. The majority of the list is comprised of organizations that support self-advocates, but generally not considered self-advocacy organizations. In order to help with the confusion, the ADDPC could consider the following distinctions to help in categorization:
 - a. a group governed by self-advocates,
 - b. self-advocate and family run groups,
 - c. disability specific groups,
 - d. groups associated with qualified vendors,
 - e. disability organizations that have social groups that serve as support groups,
 - f. youth self-advocate groups.
2. At the source of the confusion in identifying self-advocacy groups is the definition of self-advocacy. There is a population of self-advocates developing, practicing, and expressing their autonomy to further their participation and integration into society and community. Any group and its members should be at the center of defining and outlining its efforts and identity. ADDPC should support the creation of an exploratory committee to define what works for Arizona and gain consensus and buy-in from the self-advocacy contingency.
3. The demographic data collected from the respondents of the survey should be considered a dynamic document. In searches on the internet, the information is at best scattered and at times inaccurate. An online directory that includes a section to fill out vital information should be made available by the ADDPC.
4. Of the nineteen groups surveyed, the majority responded with an overwhelming need for training and support. In order for the proposed alliance to function and flourish, groups that join have to practice effective group practices. ADDPC should make the efforts to help develop groups into robust operational entities.

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5. ADDPC should consider supporting and developing self-advocacy groups from where they currently exist. Pure self-advocacy groups are few so it may be more efficient and effective to begin looking at working with disability social groups/networks that have the potential to develop into self-advocacy groups.
 6. Lastly, what the IHD-AzUCD has found by conducting this activity is that self-advocacy has a great degree of variance in the level of development from group to group. Self-advocacy has great potential to flourish in our state with proper support, planning, and leadership. In order for it to succeed, self-advocacy efforts must be given the time, support, and steady perseverance of a strong and committed partner.



APPENDICES

Please send this link to any group that should participate: <https://www.surveymonkey.com/s/SAgroupsofAZ>.