



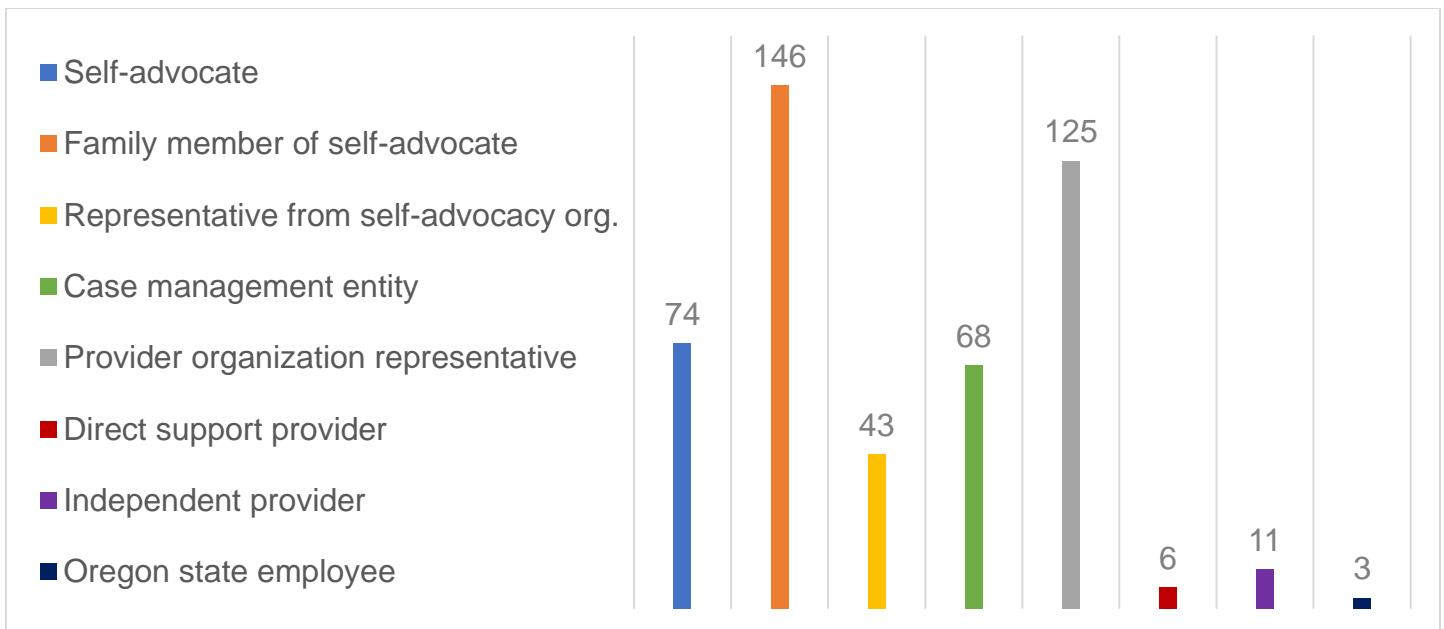
American Rescue Plan Act (ARPA) Self-Advocacy Funding Design Survey Results

The Office of Developmental Disabilities Services (ODDS) collected input from self-advocates, self-advocacy organizations, families, case management entities, and others on how to prioritize \$500,000 of funding to help strengthen self-advocacy in Oregon.

The survey was open for three weeks from February 17–March 11, 2022. There were 382 responses, and it took an average of 22:49 minutes to complete. The data below includes responses from 12 Oregon Self Advocacy Coalition (OSAC) focus group participants. This funding will be available to community partners through a formal application and procurement process during 2022 and is made possible by federal and state matched funds.

Question 1: Which group(s) do you identify with? Please check all that apply.

Below is a summary of the results from question 1:



The chart above shows the number of respondents for each option provided in the survey question, as well as the write-in responses categorized by staff. **Self-advocates total 74 of the 476 responses or 16 percent.** The largest number of responses (146) was from family members of self-advocates. The second largest number of responses (125) was from provider organization representatives, then case management entities (68), followed by representatives from self-advocacy organizations (43). The fewest responses were from independent providers (personal support worker, job coach, behavior support, foster care) (11), direct support providers (6), and Oregon State employees (3).

Question 2: How do we strengthen self-advocacy for individuals with intellectual and developmental disabilities (I/DD) in Oregon using this funding? Currently, we are considering two options for how to spend this funding:

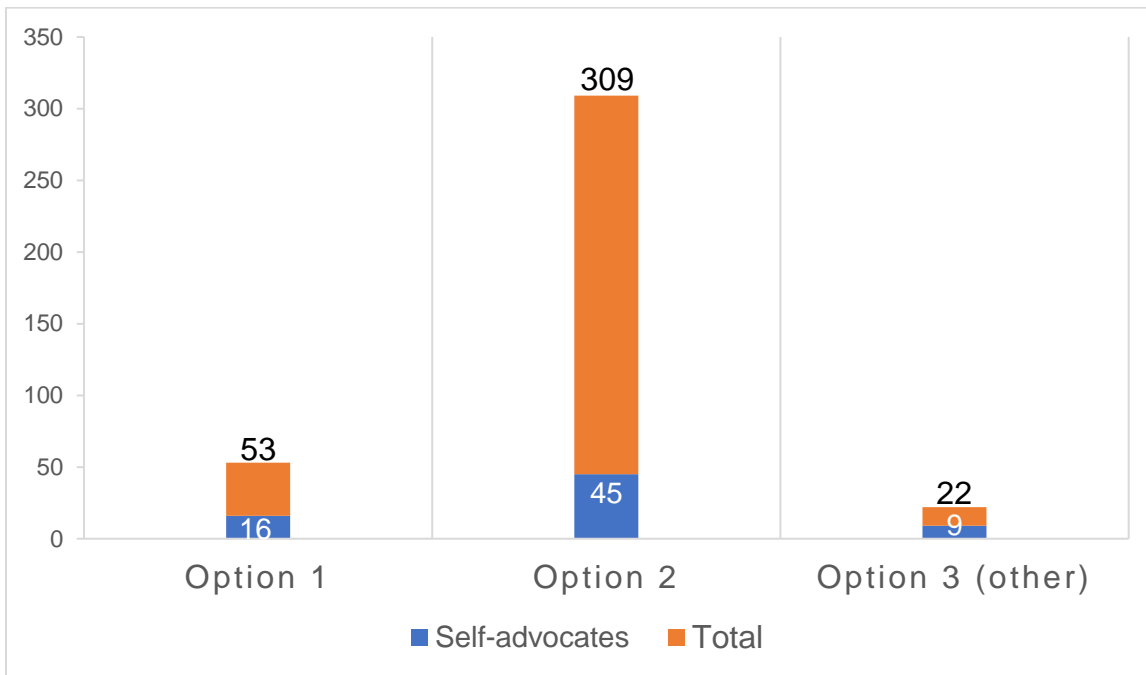
Option 1: Award the funding to one or more organizations that will create a regional infrastructure to increase self-advocate participation. This option would be limited to just a very few applicants.

Option 2: Offer flexible funding to support a variety of smaller projects and creative ideas. This option would be open for many applicants to receive smaller amounts of funding.

Option 3: Do you have additional ideas of how we can use or structure this funding to make a difference in Oregon? Please propose your idea in the “other” option below.

Please select the option you prefer.

Below is a summary of the results from question 2. Please note that some of the write-in responses for option three mentioned option one or two, plus an additional idea. All were totaled which is why the number of responses differ from the total number of respondents:



The chart above shows that the largest number of responses (80 percent) selected option two. Sixty-four percent of self-advocates who responded chose option two. Fourteen percent of the total responses chose option one. Twenty-three percent of self-advocates who responded chose option one. There were 22 write-in responses for option three, with 9 (41 percent) of those being from self-advocates or family members of self-advocates.

Here is a summary of the write-in responses from **option three (other)**: If multiple respondents answered similarly, that is reflected (for example, (3)):

- Have self-advocates make the decisions for this grant and provide the ideas (4)
- Pay for self-advocacy events and trainings (3)
- Priority to rural Oregon (2)
- Focus on underserved areas
- Funds should go directly to self-advocates
- Incentives for areas and communities that do not have a current advocacy group
- Incentivize self-advocates to come to meetings and events
- Diversity, inclusion and equity in self-advocacy groups and organizations
- Have large self-advocacy groups and organizations work with smaller groups and organizations
- Help individuals with I/DD to find community resources
- Fund high school self-advocacy-based programs
- Funding to organizations to implement trainings

- Create a program that makes people with I/DD feel worthy and seen
- Funding that goes directly to individuals
- Funds should only be awarded to someone who identifies as a self-advocate
- Make it a fair distribution
- Fund a study into alternative and equitable on-going structures for response and involvement
- Combination of both with specific targets that distinguish objectives
- Pay for assistive technology access needs for self-advocacy work
- Pay for transportation
- Pay self-advocates for their work in self-advocacy

Question 3: What are the top two items you think this funding should be used for? There are 7 options to choose from and the ability to write-in a response under 'other.'

Below is a summary of the results from question 3:



The chart above shows both the total responses to each option as well as the number of responses from self-advocates and family members of self-advocates. **The top three options favored by respondents were:**

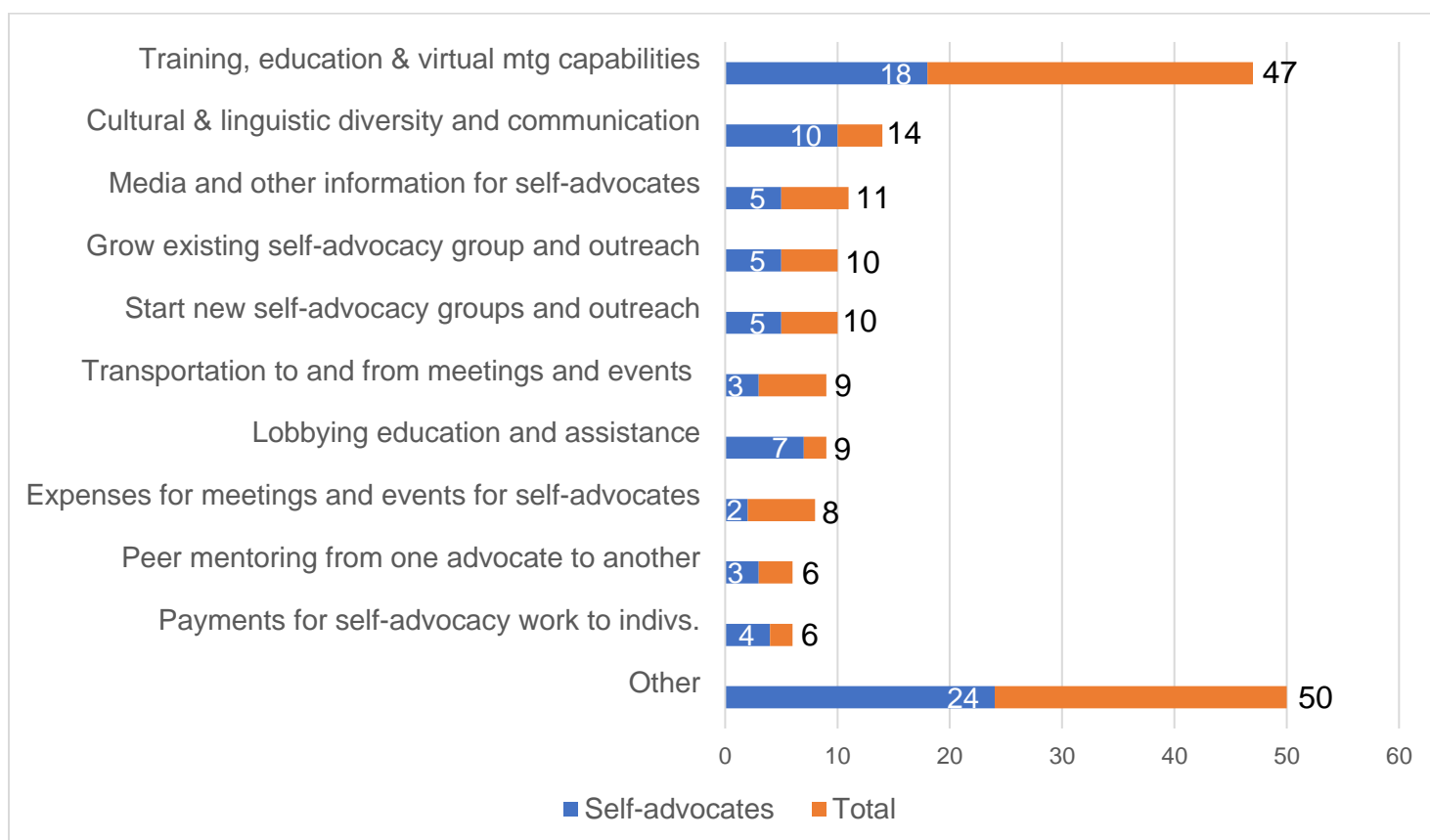
1. Self-advocacy training
2. Peer mentoring from one advocate to another
3. Grow an existing self-advocacy group(s)

Here is a summary of the **Other (write-in)** responses:

- Self-advocates should provide the ideas and oversee the work on this grant (3)
- Focus on rural areas (2)
- Pay, incentivize or offer stipends for self-advocates to participate in program engagement (2)
- Funding for individuals with I/DD to be leaders
- Funding to create a mechanism for accommodations
- Funding for a paid and dedicated support person with the correct skills to understand self-advocacy work and assist individuals with I/DD
- Assistance for self-advocates to participate in Legislative days
- Social workshops
- Diversity, equity and inclusion
- In person meetings and activities
- Legal funding
- Materials for classroom or Zoom trainings
- Funding to revamp how advocacy and involvement is built into service delivery in an inclusive and equitable manner to ensure impacts are understood and benefit those most in need of support
- Use social media to inform and recruit self-advocates

Question 4: Do you have ideas about how to use this funding to improve self-advocacy in Oregon or other comments?

Below is a summary of the results from question 4:



The chart above shows common themes pulled from the write-in responses. Responses were grouped and categorized as seen in the chart by staff. Many of the responses were reiterating their choice for question 3, so most categories in the chart are similar. Both the total responses in each category, as well as the number of responses from self-advocates and family members of self-advocates are shown. **The top three categories from respondents were:**

1. Self-advocacy training, education and virtual meeting abilities
2. Cultural and linguistic diversity, and communication
3. Media and other information for self-advocates

There were many ideas shared in responses to this question that were too varying to categorize. Below is the summary of those responses as well as highlighted responses from all categories. If multiple respondents answered similarly that is reflected (for example (3)):

- Share the results of the survey with self-advocates (14)
- Funding for lodging for meetings and events (7)
- Diversity, equity and inclusion of participant's needs to be worked on in self-advocacy groups (6)

- Funds to provide accommodations and supports to individuals who would like to be a self-advocate (5)
- Support self-advocates be involved in the legislative days and process (5)
- Any funding that goes to paid positions should be focused on funding self-advocate's expenses when involved with supporting the growth of self-advocacy (4)
- Incentives, stipends or payments for self-advocates to participate in meetings (4)
- Return to in-person meetings and events (3)
- Distribute information broadly by using different formats (3)
- Provide different options for participation in meetings, trainings and events (2)
- Coaching on speaking in public about issues (2)
- Create additional funding to sustain self-advocacy efforts after the funds for this grant are expended (2)
- Providing funding for targeted self-advocacy trainings projects and programs (2)
- Get out in community via Zoom and in person
- Recruitment of new self-advocates
- Skill building
- Regularly scheduled meetings for self-advocates
- Participation in stakeholder meetings by self-advocates
- Hire self-advocates and support staff to develop trainings
- Assist groups build their self-advocacy network
- Address lack of available places to gather and self-advocate
- Self-advocacy programs that are school based; start young
- Targeted outreach
- Technical assistance
- Have case management entities empower clients to self-advocate
- Help in operating self-advocacy groups to new smaller groups (such as rural areas)
- Funds for interpreters (American Sign Language and other languages)
- funding should be allocated on a regional basis with regions and self-advocates determining the priorities allocated funds
- Having a monthly calendar of events posted online and other places
- Self-advocacy summer camps
- Provide online materials and trainings
- Bring self-advocate locations and organizations together
- Supporting groups that can engage more people to be self-advocates

- Create a brochure with a list of classes, trainings and events about self-advocacy and agencies to hand out
- Safe activities in communities for people with I/DD to practice self-advocacy skills
- Media and social media campaign on self-advocacy for people with I/DD
- Resources that guide creating or joining existing networks
- Provide cause concepts that larger networks can focus on to impact services
- Focus efforts and opportunities
- Provide resources that can be implemented at the individual support plan (ISP) team level to support these efforts
- Community developmental disabilities program (CDDP) self-advocacy groups
- Get as many people as possible with I/DD to attend community meetings and legislative events
- Peer to peer mentoring
- Pay or help pay for conferences
- Have trainings be both on the computer using Zoom and in person to reach a larger number of individuals
- Self-advocate's conference
- Focus on youth
- Pay for assistive technology access needs for advocacy work
- **There were multiple recommendations for the types of trainings for self-advocacy in the survey results included in “other” responses (above). They are:
 - Family trainings
 - Training “average” person to accept choices made by an individual with I/DD
 - Train self-advocates and providers
 - Train personal support workers and state staff in providing needed supports during meetings, trainings and events to self-advocates who need supports
 - Training group specific
 - Training in methods of non-verbal communication
 - Trainings on practicing self-advocacy
 - Training on how to self-advocate with law enforcement
 - Train self-advocates and providers
 - Parent and youth trainings in self-advocacy

Suggested parameters from survey:

- Let self-advocates with I/DD make the decisions about this grant (5)
- Use data to guide the process. The challenge with established organization is they tend to have implicit biases and standard, frequent participants, but there is a benefit to that history. New projects can have innovative ideas that work for a specific area or purpose.
- Diversity of participants and advocacy organizations
- Clear monitoring guidelines
- Funding should go directly to self-advocates
- Transparency

Note: Responses from the survey that did not apply to self-advocacy but applied to other services or grants were sent to the appropriate teams.

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