



## **SNAPSHOT:**

Results of The Arc's Long Range  
Planning National Stakeholder  
Survey, 2019

## National Survey Results from The Arc's Strategic Framework for the Future

The Strategic Framework for the Future of The Arc provides a blueprint to guide us into the future, with a dynamic Vision, clear Goals, and the Strategies and Tactics that will get us there. The plan reflects our dedication to people with intellectual and developmental disabilities, their families and supporters, and their collective futures. How was this new framework influenced by The Arc's constituents? With **our mission** in mind, we engaged in a two-year participatory process to seek input from a variety of constituents, including:

- ▶ **Hundreds of Chapter leaders**
- ▶ **56 key leader interviews**
- ▶ **A nationwide stakeholder survey with more than 4,000 respondents**
- ▶ **18 large and small group meetings with self-advocates, chapter leaders, and alumni of The Arc, among others**

This work was led by our Long-Range Strategic Planning Committee.

To understand how we arrived at our new Strategic Framework, we want to share a summary of the insights gained from our stakeholder survey.

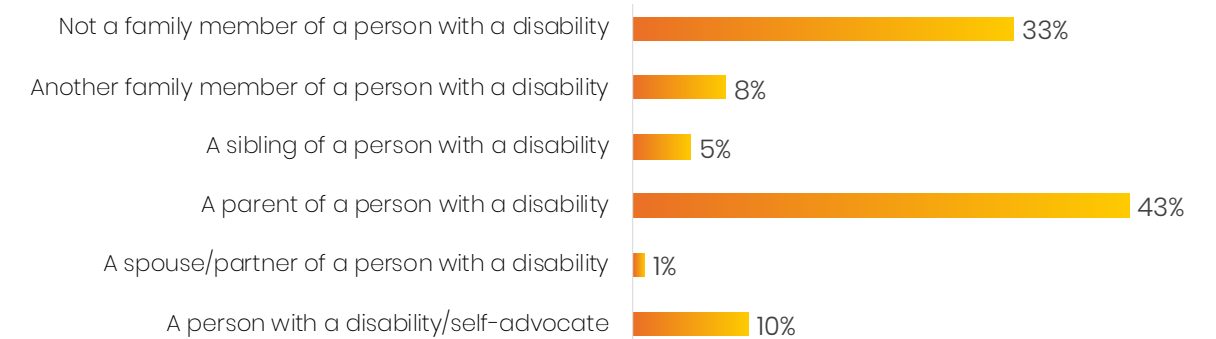
This summary is not inclusive of every question and response to our robust survey. It is intended to be a broad overview of key themes.



## Who Responded to our Survey

Over 4,000 individuals, representing all 50 states and the District of Columbia, responded to our call for input on our new strategic plan. Most respondents answered the majority of survey questions; however, many questions were not required and thus each respondent's completion rate may not have been 100%.

### What best describes your identity?

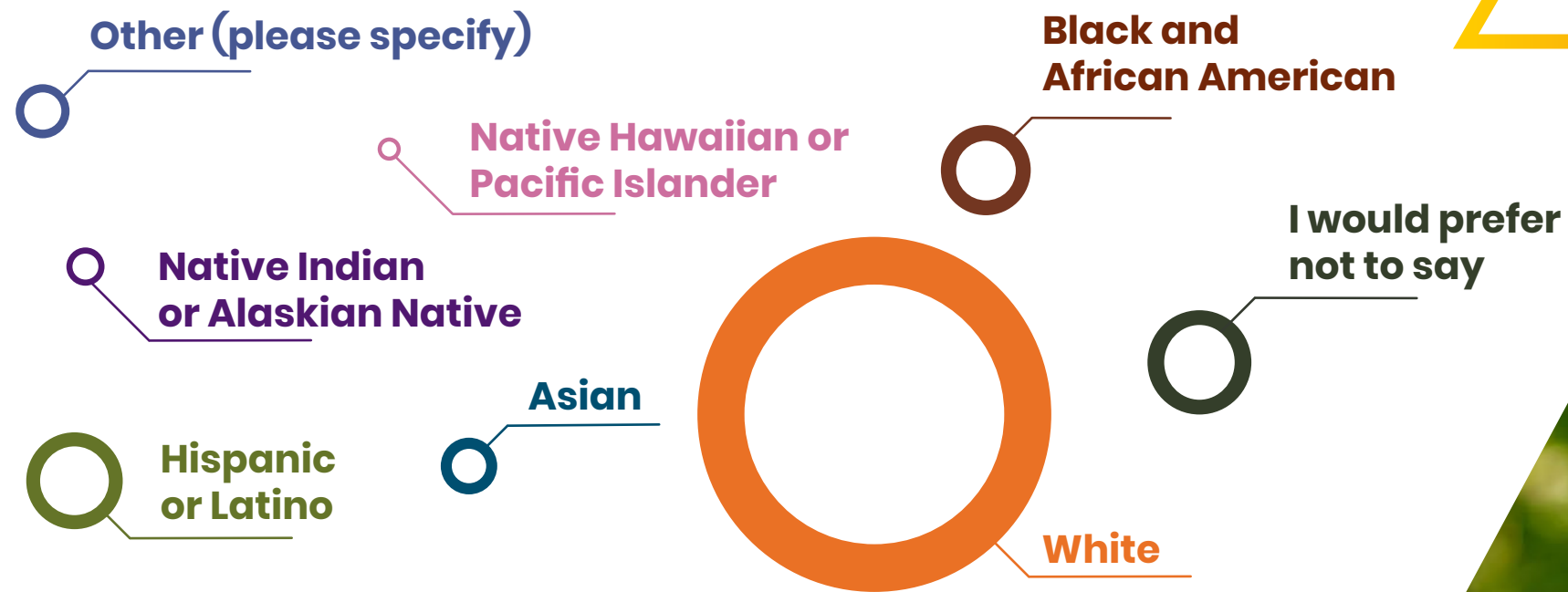


*46% of respondents had no connection to The Arc.*

Why does that matter to us in our planning? We want to grow the disability rights movement and expand The Arc's role as a leader in that movement. To do this, our planning needed to be inclusive of the perspectives of people who are not currently connected to us in a formal way.

We also highly value the input of our members, chapter staff, and boards. Staff, board members, and volunteers of a chapter at the local, state, or national office level responded to this survey, and were heavily involved in interviews and small and large group meetings throughout this process.

While we engaged with hundreds of other organizations to help us disseminate the survey as widely as possible—including many that focus on serving and supporting marginalized communities—our exhaustive outreach efforts ultimately did not generate a sample that is representative of the American people and of the national disability community. The majority of our sample was white women.



We also made a concerted effort to garner as much participation from self-advocates in the survey as possible and though we managed to get responses from nearly 400 individuals with disabilities, The Arc always strives to further include the voices of people with disabilities in all that we do.

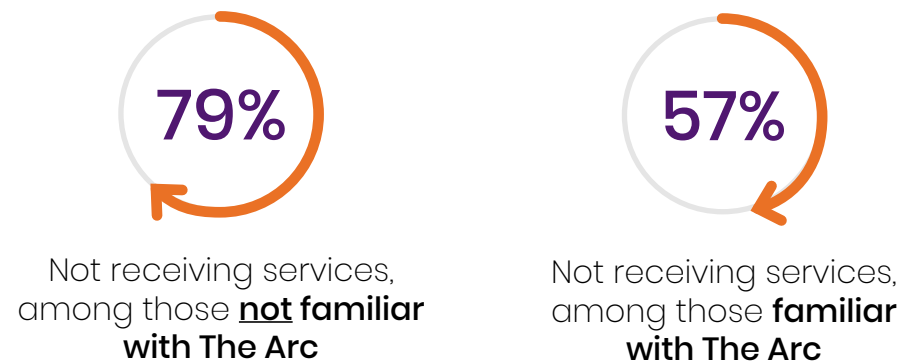
In alignment with the utmost value which we place upon the experiences and opinions of people from diverse racial, ethnic, cultural backgrounds, sexual orientations, and gender identities, we will continue to seek input from marginalized groups in our pursuit of true access, equity, and inclusion in all our efforts.



# Services Are Key to Living Life of Own Choosing, Now and in the Future

Currently, one of the biggest issues facing people with IDD and their families is the availability of direct services and access to funding for those services. This survey was conducted before the COVID-19 pandemic, but the data shows that even then, the majority of respondents are not receiving vital support services and many still must pay for these services out of pocket.

**We learned in this survey that people who are not familiar with The Arc are much more likely to not have access to services:**



**How important are the services people receive to them living life the way they want?**

98% said the services were important or very important.

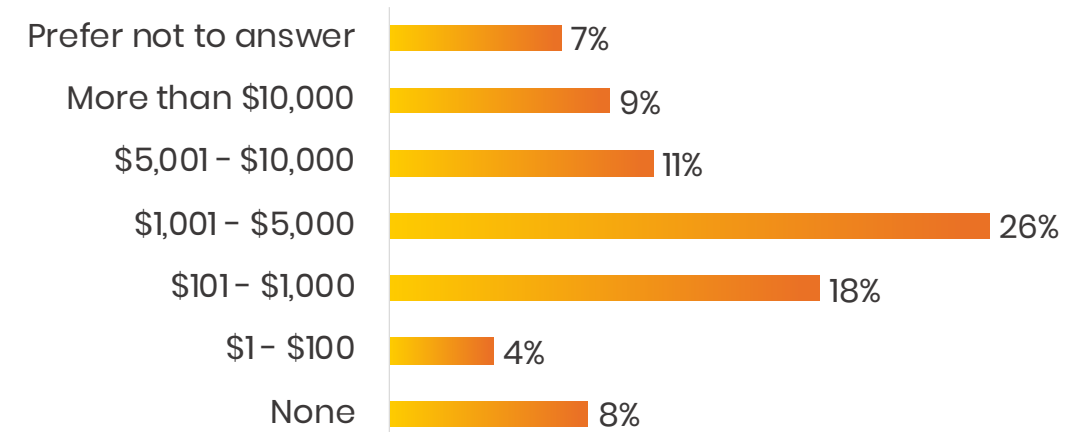
**People are looking ahead to the future and the services they will need to live the life of their choosing.**

Respondents rated services on a scale from not at all important, to very important. More than 60% of respondents rated the following as very important:

- Advocacy services and training
- Counseling on benefits like SSI and Medicaid
- Competitive integrated employment
- Employment supports
- Mental health, behavioral health care
- Navigating, coordinating, planning services
- Supports to live on your own, outside of the family home
- Supplemental Security Income (SSI) Disability Benefits
- Transportation services or support



Regardless of whether families are a part of the service delivery system or not, **people are spending out of pocket** on medical services, equipment, supplies, therapies, and other supports and services for the individual with disabilities. These results reflect what respondents spent in the previous year.



Of the respondents\* who shared that their services are funded via Medicaid, there remain **numerous barriers to receiving or utilizing these funded services.**

There is a waiting list for services	41%
These services are not available in my area	27%
I don't know where to find the needed services	15%
I don't know what service providers I can trust	31%
I can't afford the services	12%
Other (please specify)	45%
Prefer not to answer	33%

**For those that indicated "other", several themes emerged in their explanations:**

- Not enough qualified staff at local agency to meet needs
- Difficulty with finding services that match need of individual with disabilities
- Quality of available services
- Funding challenges

*\*respondents selected all that applied*



## Advocacy Needed on Many Fronts

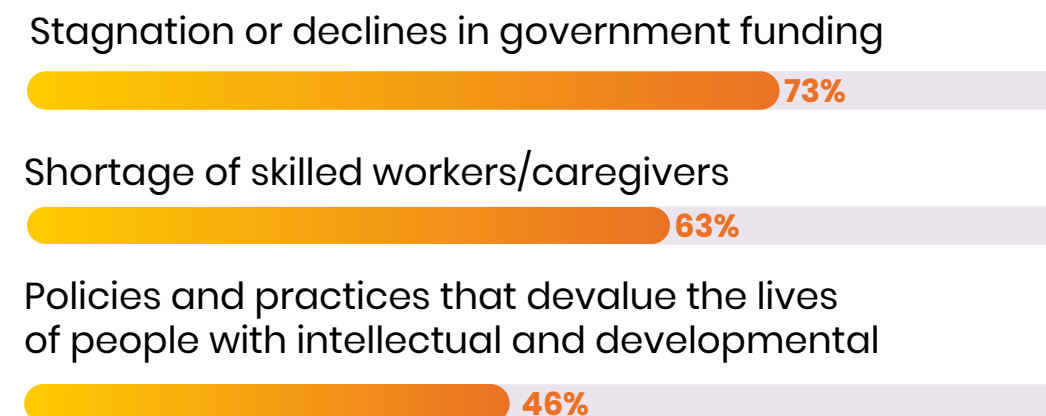
We wanted to know what people imagine will be the most critical issues facing the IDD community in the future. Survey results are clear: advocacy, both system change and individual advocacy, is critical to creating better life opportunities for people with IDD.

Where Advocacy Will Be Needed	System Change	Individual Advocacy
Federal government	80%	68%
My state government	89%	84%
My local government	61%	67%
My local school system(s)	51%	59%
Local health care providers	55%	58%
Local employers	62%	62%
Local retail establishments	33%	37%
Local transportation services	58%	57%
None of the above	0%	2%

Two thirds or more of respondents rated as very important the following issues:

1. Access to quality health care
2. Housing/community living
3. Federal benefits
4. Family supports
5. Quality improvement of services and supports
6. Employment
7. Self-advocacy
8. Civil rights/the Americans with Disabilities Act
9. Education access

The top three things that will hurt supports for people with intellectual and developmental disabilities in the U.S. over the next 10 years:



### How do we define these terms?

**Systems change:** advocacy that seeks to make policies more responsive to needs of people with intellectual disabilities

**Individual advocacy:** advocacy to help a person obtain services and support or prevent violations of their rights



# Being the Catalyst for Change

How people with IDD are viewed and valued in our society has been a huge challenge for decades. The Arc is committed to being a force for change in perceptions and attitudes. And our survey results demonstrate that people are with us.



**87% of respondents agree with the following statement:**  
The human dignity of people with IDD is often not respected in our society

**79% of respondents agree with the following statement:**  
People with IDD are rarely portrayed, or portrayed accurately, in the media

## Top opportunities respondents think could positively impact the state of intellectual and developmental disabilities in the U.S. over the next 10 years:

Increasing support from the business community to create new jobs, employee supports, and corporate partnerships



Increase in establishing partnerships to solve social challenges



Philanthropy (e.g. charity organizations) waking up to disability rights and society beginning to understand collective strength of diversity



Increased availability of technology to reach underserved populations



**The business community has a huge role to play in improving the quality of life for people with IDD.** Respondents rated the following activities as helpful or very helpful to our cause:

Employing more people with disabilities



Providing more support and assistance for employees who are caregivers for loved ones with disabilities



Developing new products and services that support people with disabilities to live in the community



## The Arc is critical in the lives of people with IDD.

81% responded that the organization is helpful or very helpful in the lives of people with disabilities.

## What makes The Arc unique?

- ▶ Our national presence
- ▶ We serve individuals and families across the lifespan
- ▶ Depth of expertise and experience in public policy advocacy

85% of respondents ranked it as highly important to be a part of a nationwide movement dedicated to people with IDD.

## Join us as we move forward.

### OUR VISION

The Arc's vision is for people with intellectual and developmental disabilities to be valued members of their communities, with the opportunity to realize their full potential and a future that is secure.

### OUR GOALS

To make this vision a reality, The Arc will work to achieve the following Goals.

1. Every member of society recognizes and respects the human dignity of people with IDD.
2. People with intellectual and developmental disabilities are masters of their own lives and destinies, with help from family, friends and other supporters if needed.
3. People with intellectual and developmental disabilities, and their families, have timely access to the quality supports and services they need and want to achieve a life of personal significance.
4. The Arc is an even stronger, more diverse force for change, capable of wielding power with and on behalf of people with IDD and their families at the local, state and national level.

Learn more about our specific strategies and tactics by reading our full [Strategic Framework for the Future of The Arc](#).





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The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.