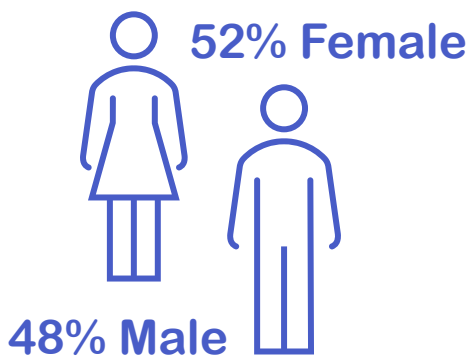
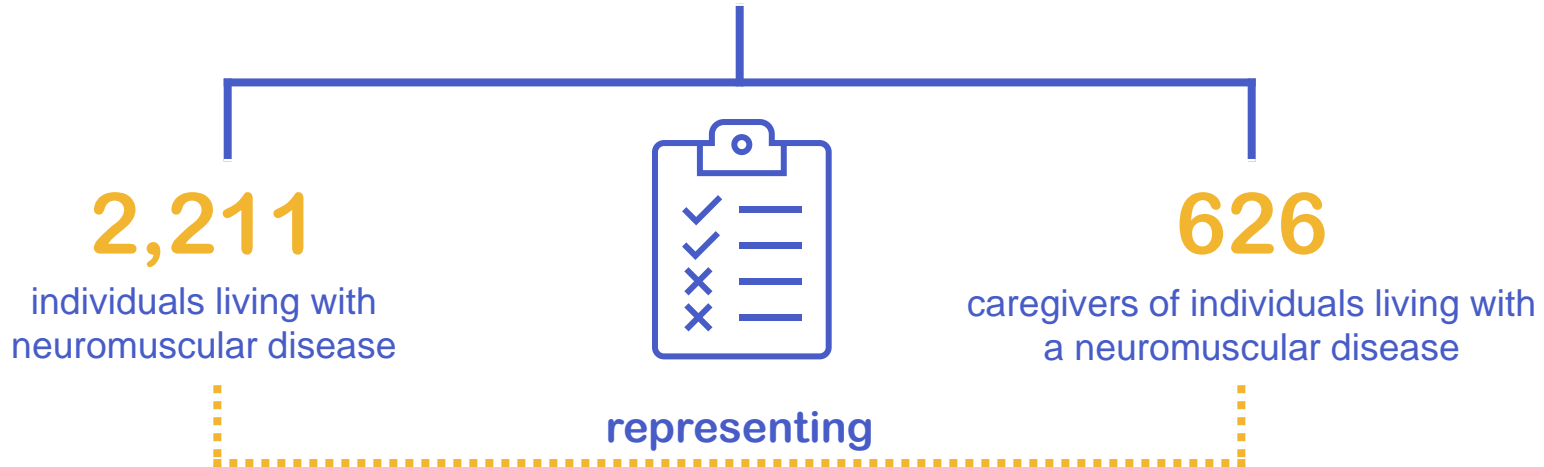


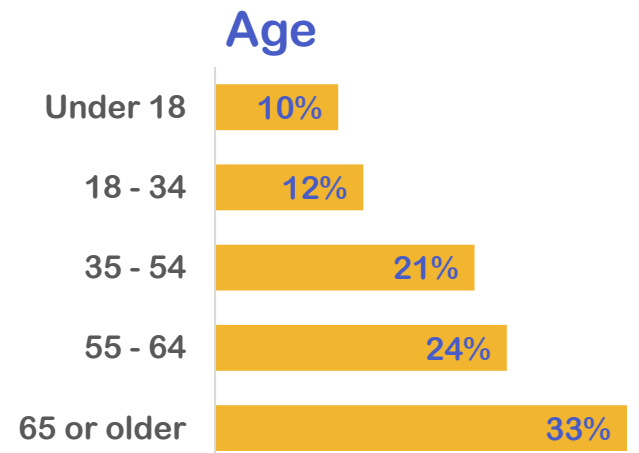
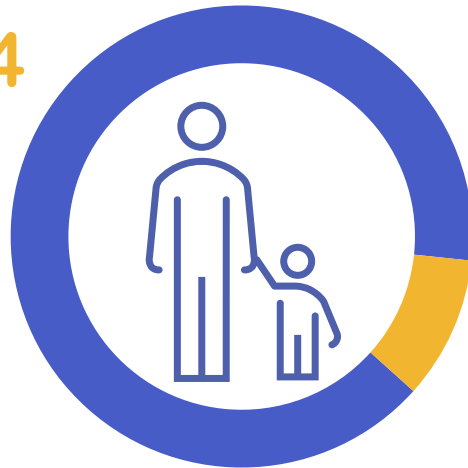


A survey of the neuromuscular disease community about access topics impacting those living with and caring for individuals with neuromuscular disease

2,837 community members completed the survey



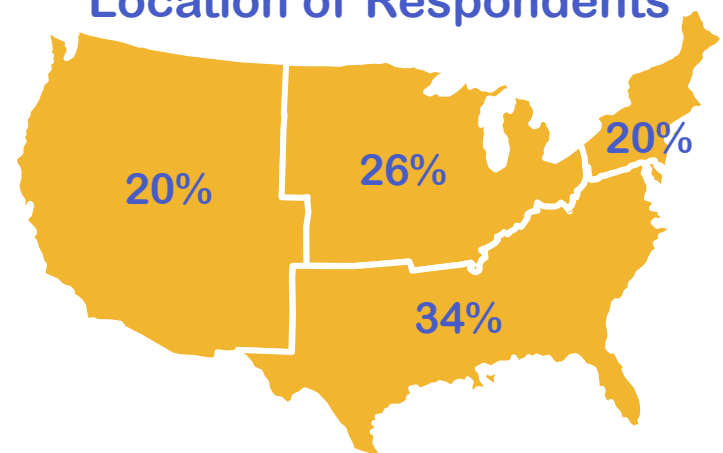
2,554 adults



Most Common Diagnoses

- CMT (Peroneal Muscular Atrophy)
- Limb-Girdle Muscular Dystrophy
- Myotonic Muscular Dystrophy (Steinert's Disease)
- Facioscapulohumeral Muscular Dystrophy
- Duchenne Muscular Dystrophy

Location of Respondents





Insurance Coverage

79%

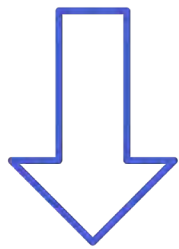
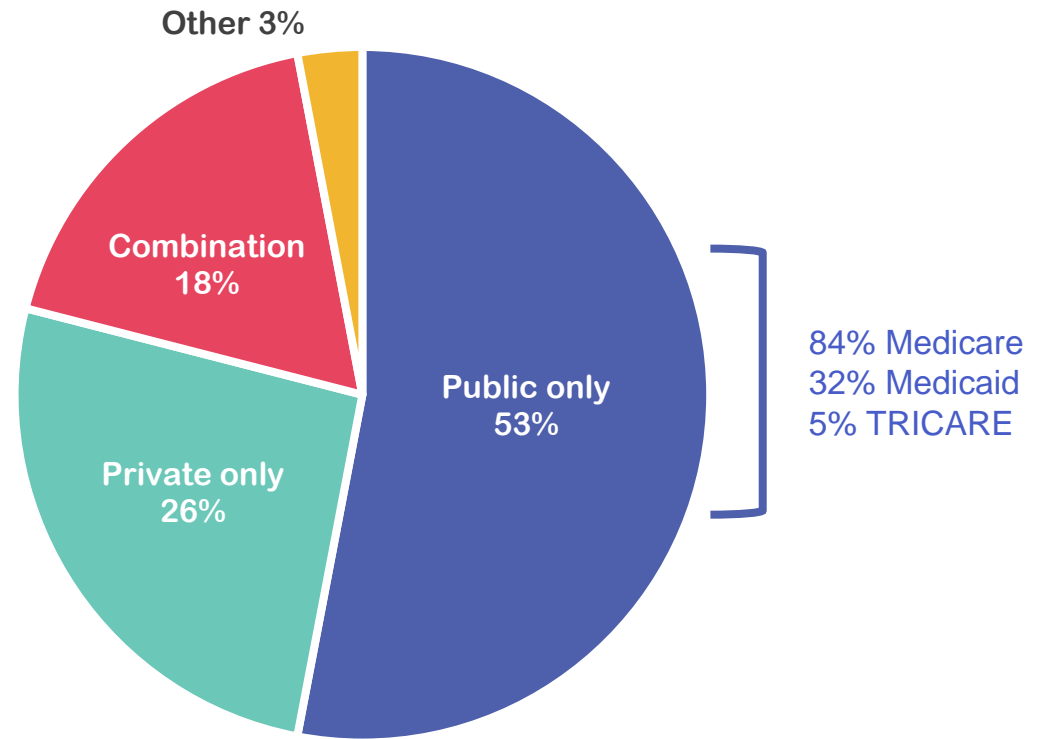
are familiar with the benefits and coverage of their insurance plans and understand how and where to purchase health insurance

57%

say their insurance plan covers mental health services

51%

Have been denied access to coverage



Denied Services



Equipment

34%



Medications

23%



Therapies

17%



Specialty Care

15%



Provider 5%

Why?

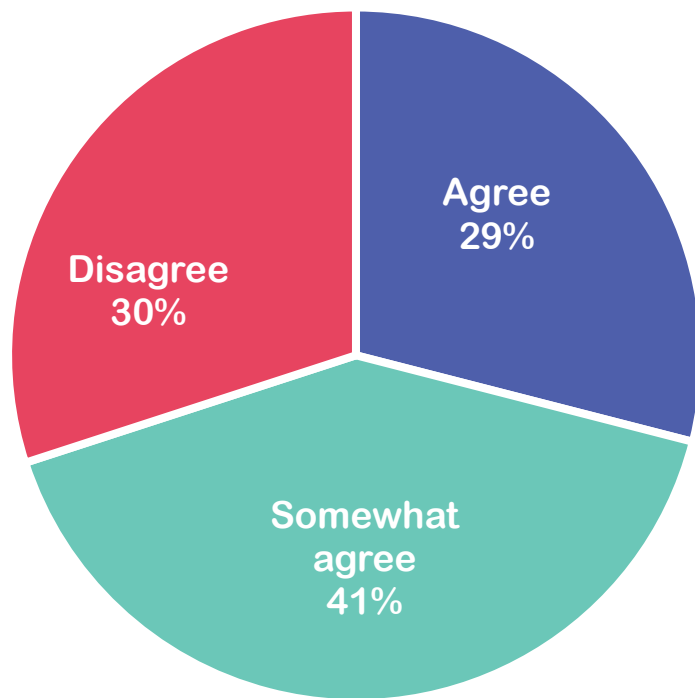
59%

equipment was deemed "not medically necessary"



Finances

“I feel confident about my financial future.”

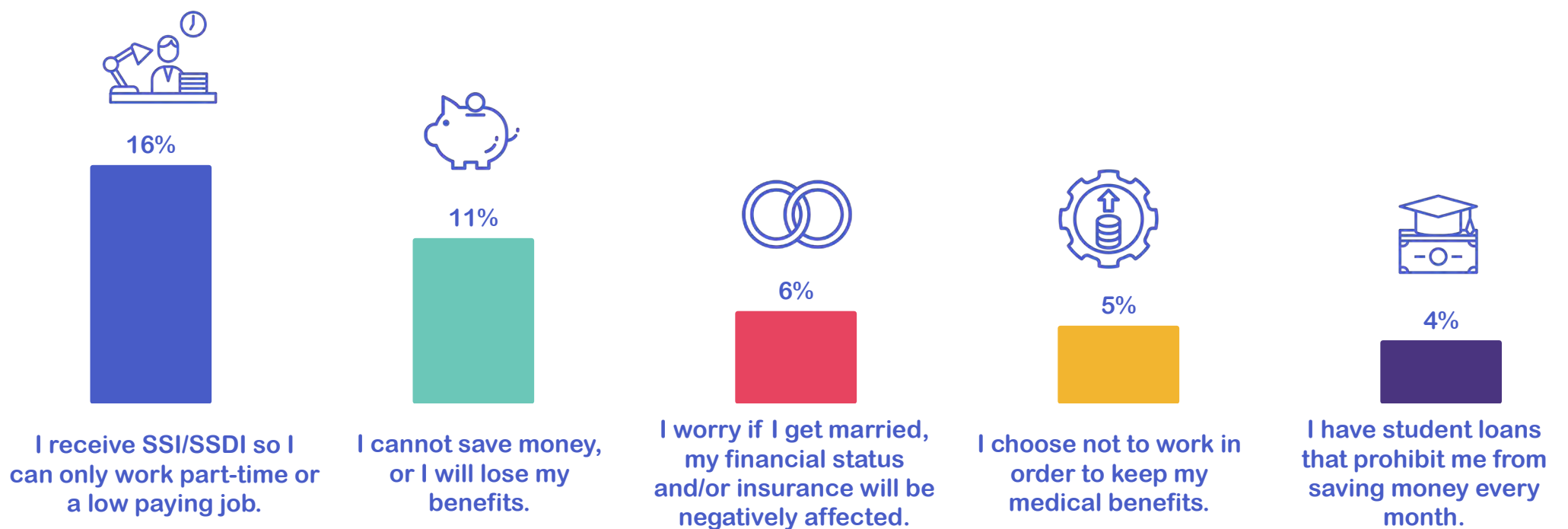


We can't have any assets or money to get disability. I feel encouraged to have nothing in order to get more help for my son. Yet I have 3 other children. The system fails those that need the help the most.

I am unable to get SSDI because I have a master's degree, but my disability affects my ability to even do sedentary work.

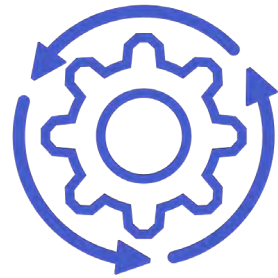
My state requires persons on disability to work in order to be eligible for Medicaid. It doesn't matter if Social Security deems you totally disabled.

Financial Barriers





Employment



21%

Working full or part time



35%

Not working/ disabled



27%

Not working/ retired

75%

Believe their employer values diversity and inclusion in the workplace

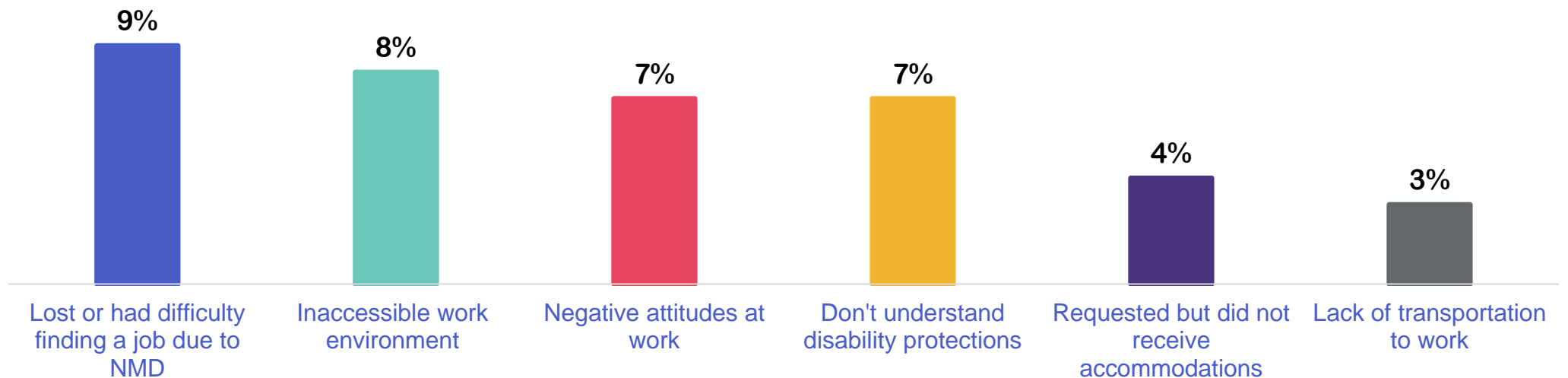
66%

Of those surveyed believe more resources are needed to support diversity and inclusion of the disability community at work

27%

Have faced barriers at work

I experienced access barriers every single day whether it be getting fired because I use a wheelchair, not being able to enter a business because there is no handicap entrance, or not getting hired because of my wheelchair despite my incredible resume.





Education

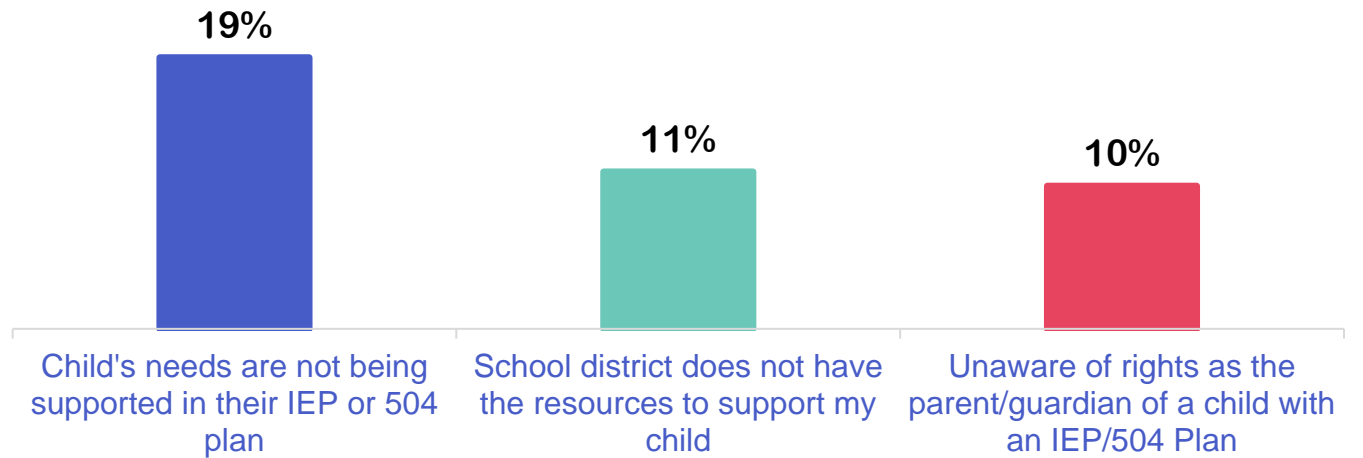
K12



47%

of Caregivers are caring for a K-12 aged child

K12 Barriers



Higher Ed



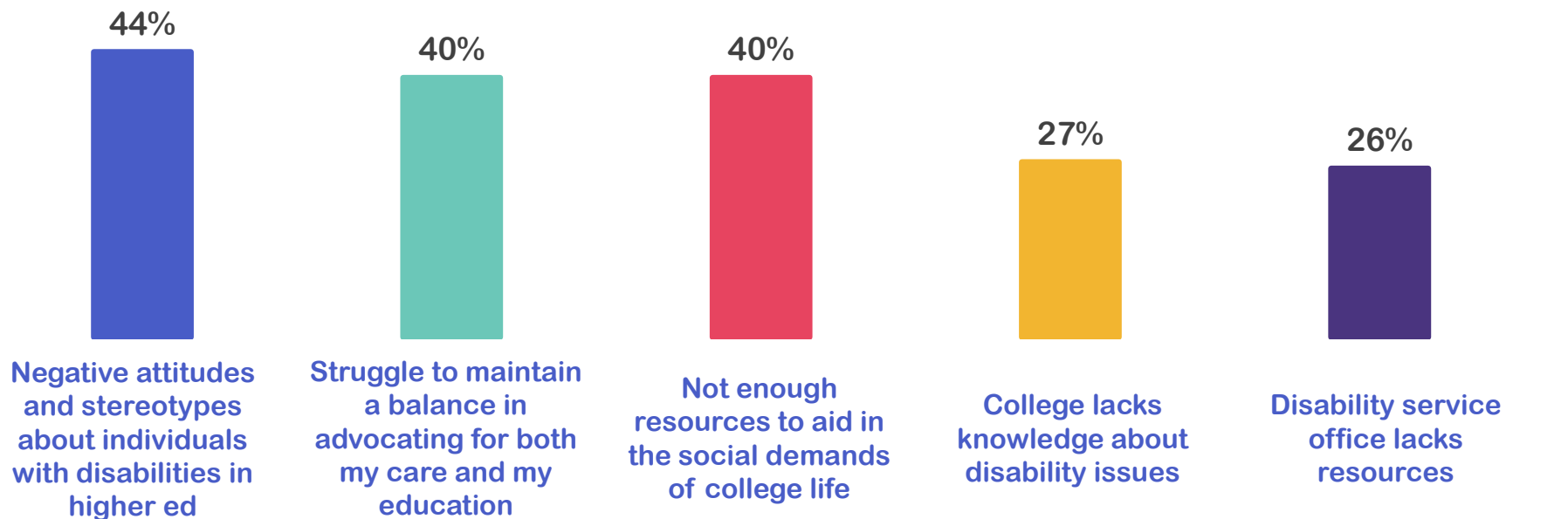
8%

of those surveyed pursued post-secondary education in the past 5 years

72%

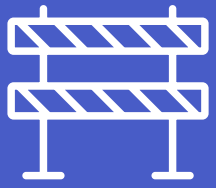
Of recent students surveyed believe more resources are needed to support diversity and inclusion of the disability community within their student body

Other Higher Ed Barriers



66%

Say there is lack of information about the process for funding and personal assistance



Additional Barriers Mentioned

27% Public access

Access to businesses, public and private. General access to public transportation and local sidewalks.

15% Restrooms

I need help in and out of the women's restroom and my significant other is a male, which is challenging due to lack of family restroom availability. Most bathrooms do not have push button door entrances.

4% Transportation

My big problem is getting around another city, if I travel to visit with my power chair. Wheelchair taxis are scarce or very expensive or need to be booked on a weekday only before your planned schedule need. Or you need to qualify, which requires months of fore-planning

4% Equipment

I have a horrible time accessing DME, especially through my health provider. I wanted to try an upright walker with arm support. The PT from the neuromuscular clinic just provided a website where I could purchase one.

4% Housing

It's nearly impossible to find ADA adapted apartments. Brand new apartment buildings are going up left and right, but none of them have ADA units. "Wheelchair accessible" yes, but not adapted with kitchens and bathrooms that work for someone actually dependent on their mobility device.

9% Medical

I need a knowledgeable doctor in my area to start seeing (neurologist). And I would like to start the gene therapy, but I don't know how or who to contact.

18% Travel

Not being able to fly safely and securely in my own wheelchair. Having to transfer to an aisle chair to be loaded onto the airplane is unbearable and dehumanizing.

7% Financial

I have to advertise my condition with assistance devices from the Stone Age because that is all insurance covers. And since I am still able to work, I must be fine and can't get any help or tax breaks to help or understanding of what my needs are.