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

2,211 individuals living with neuromuscular disease
626 caregivers of individuals living with a neuromuscular disease

2,554 adults
283 children

52% Female
48% Male

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
- 20%
- 26%
- 34%
- 20%
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%

84% Medicare
32% Medicaid
5% TRICARE

59% equipment was deemed “not medically necessary”
I receive SSI/SSDI so I can only work part-time or a low paying job.

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 cannot save money, or I will lose my benefits.

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

I worry if I get married, my financial status and/or insurance will be negatively affected.

I choose not to work in order to keep my medical benefits.

I have student loans that prohibit me from saving money every month.

“I feel confident about my financial future.”

Disagree 30%

Agree 29%

Somewhat agree 41%
Employment

- 21% Working full or part time
- 35% Not working/disabled
- 27% Not working/retired

Believe their employer values diversity and inclusion in the workplace: 75%

Of those surveyed believe more resources are needed to support diversity and inclusion of the disability community at work: 66%

Have faced barriers at work: 27%

- 9% Lost or had difficulty finding a job due to NMD
- 8% Inaccessible work environment
- 7% Negative attitudes at work
- 7% Don't understand disability protections
- 4% Requested but did not receive accommodations
- 3% Lack of transportation to 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.
Negative attitudes and stereotypes about individuals with disabilities in higher ed
Struggle to maintain a balance in advocating for both my care and my education
Not enough resources to aid in the social demands of college life
College lacks knowledge about disability issues
Disability service office lacks resources

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

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.

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.

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.

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 foreplanning.

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.

4% 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.