

Data in this report are from **41 participants** with SCN2A. **23** females and **18** males are represented.

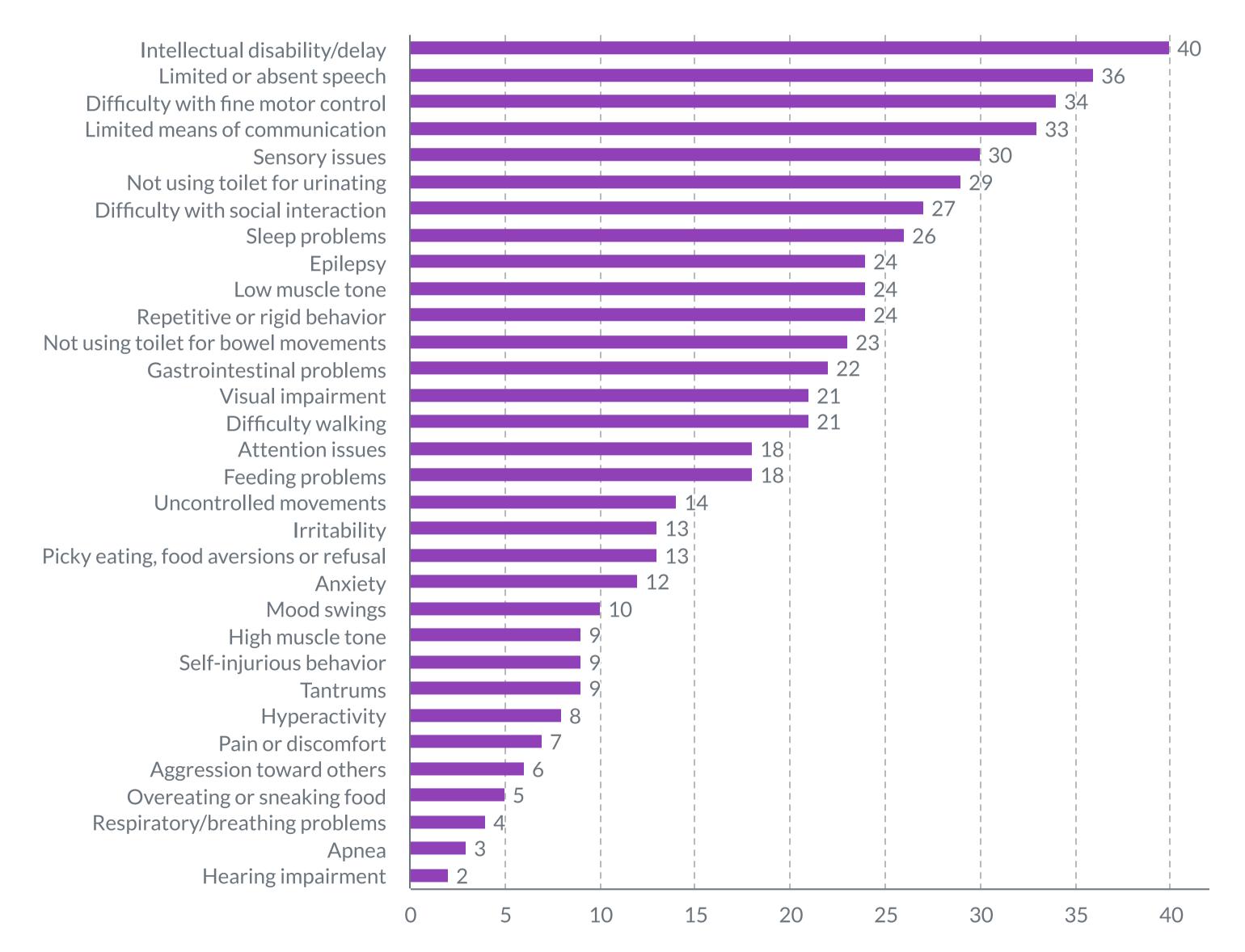
Participants were between **1 and 34** years old. The average age was **11** years.

Simons Searchlight created this Voice of the Community survey to hear about the challenges that family members experience related to their genetic condition.

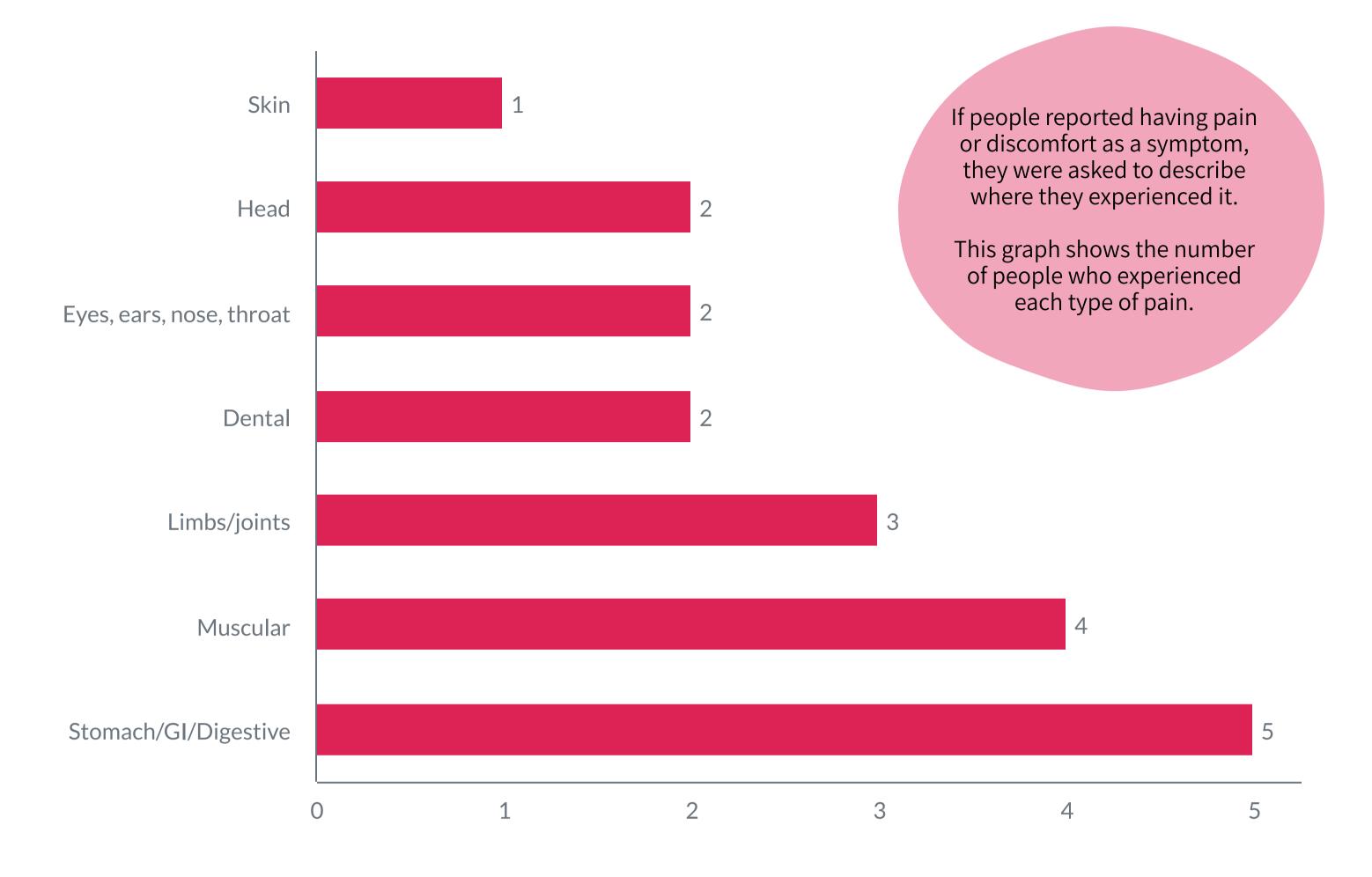
Researchers use Voice of the Community surveys to help inform assessment and treatment decisions from a patient-centered approach.

Symptoms Reported for People with SCN2A

Caregivers were asked to report all the current symptoms experienced by their family members with SCN2A. A list of 32 symptoms was provided. Bars in the graph show the number of people who currently experience the symptom.

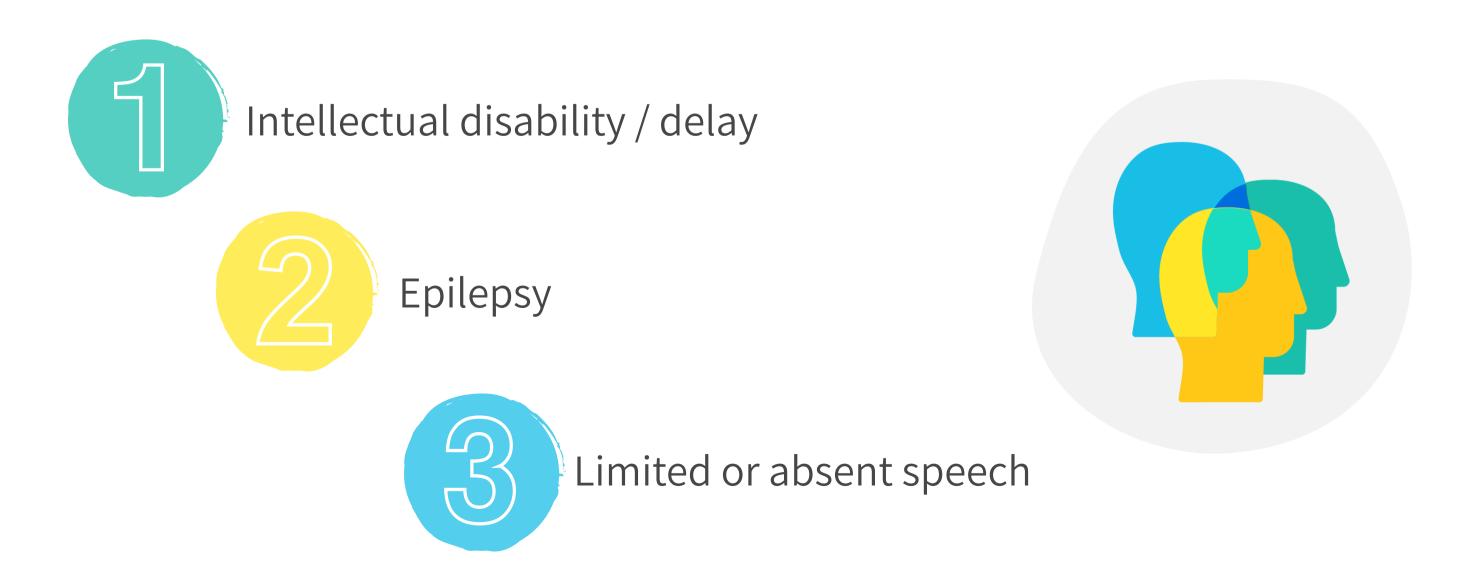


Type of Pain or Discomfort



Symptoms with the Greatest Impact

Caregivers were asked to rank 3 symptoms that have the most impact on them or their family members with SCN2A. Below, we show the 3 symptoms that were reported to have the most impact.



Symptoms with a High or Very High Impact

Caregivers were asked to rate the impact for every symptom experienced by their family members with SCN2A. They rated the impact for each symptom from 'no impact' to 'very high impact.'

This table shows the number of people with SCN2A who are either highly impacted or very highly impacted by a given symptom.

Intellectual disability / delay	35
Limited or absent speech	30
Limited means of communication in any way	25
Difficulty with fine motor control (using hands and fingers)	22
Not using the toilet for urinating	16
Sleep problems	16
Not using the toilet for bowel movements	15
Epilepsy	14
Difficulty walking	13
Low muscle tone	13
Attention issues	13
Difficulty with social interaction	13
Gastrointestinal problems	12
Sensory issues	11
Visual impairment	10
Repetitive or rigid behaviors	9
Feeding problems – physical swallowing issues	9
Anxiety	8
Mood swings	7
Hyperactivity	7
Uncontrolled movements	6
High muscle tone	5

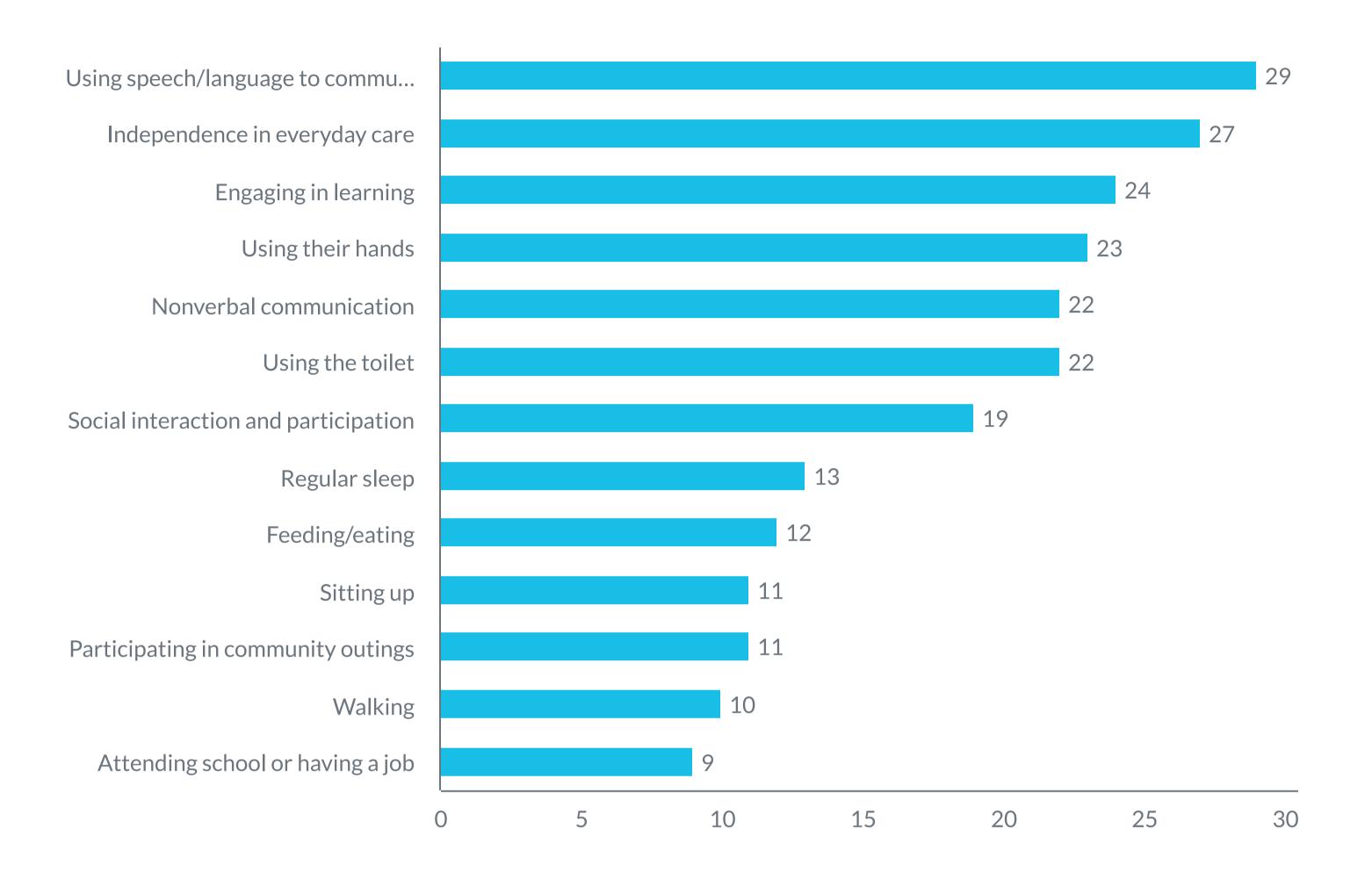
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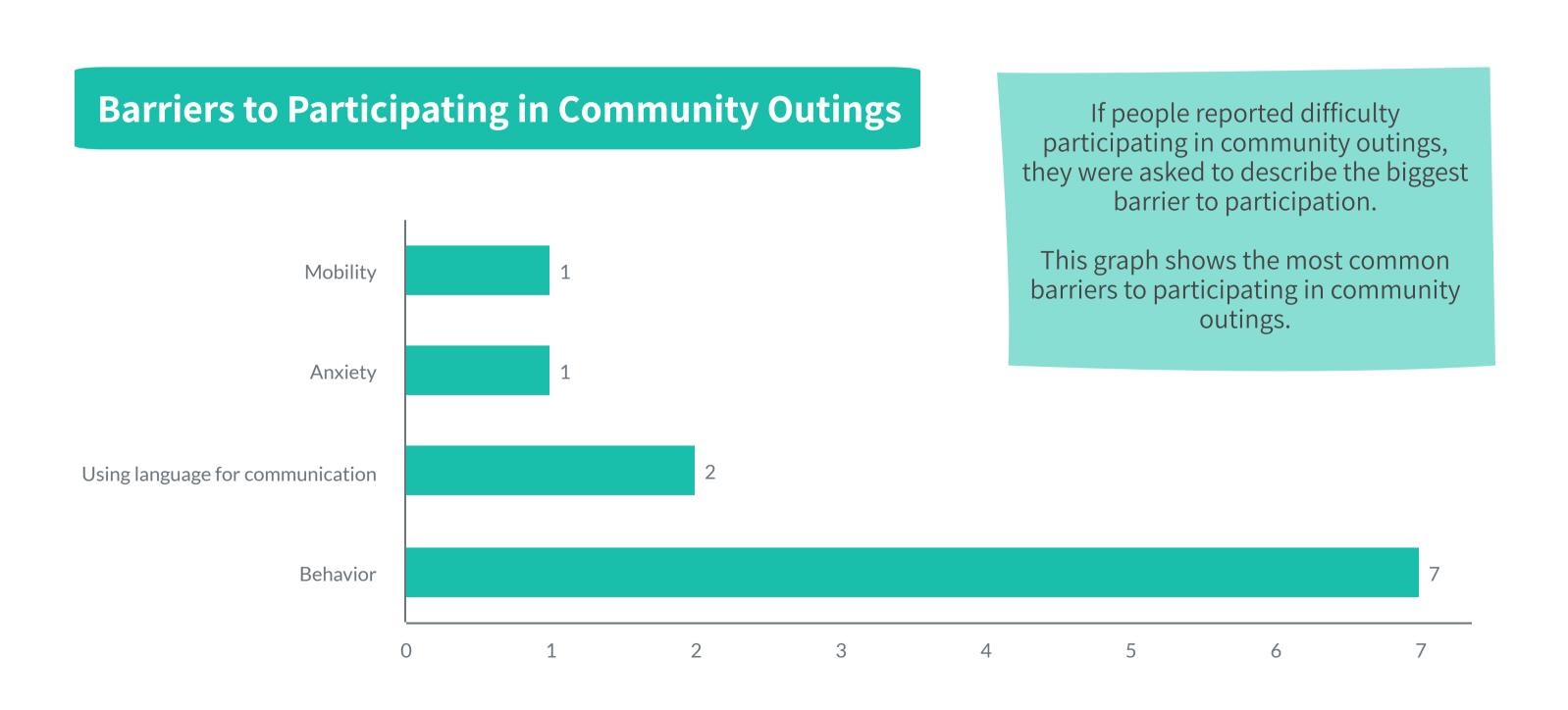
- People may be shown in more than one row if they reported multiple symptoms.
 Symptoms that affected at least 5 or more people were included.

Most Challenging Daily Activities

Caregivers selected all the daily activities that are most challenging for their family members with SCN2A.

Bars in the graph show the number of people with SCN2A that have trouble with each daily activity.





Important Targets for Drug Treatments

Caregivers were asked to rank 3 treatment targets that are most important to their family members with SCN2A. This graph shows the 3 treatment targets ranked as most important.



Reduce/stop seizures





Improve learning and cognitive ability



Improve speech / language

Simons Searchlight is grateful to all the caregivers representing their family members. This survey is an initial step to better understand the symptoms and challenges faced by your community. Your participation can help guide future research efforts to fully describe the needs and priorities of your community and plan for effective treatments.





Thank you

for contributing knowledge to Simons Searchlight!





