

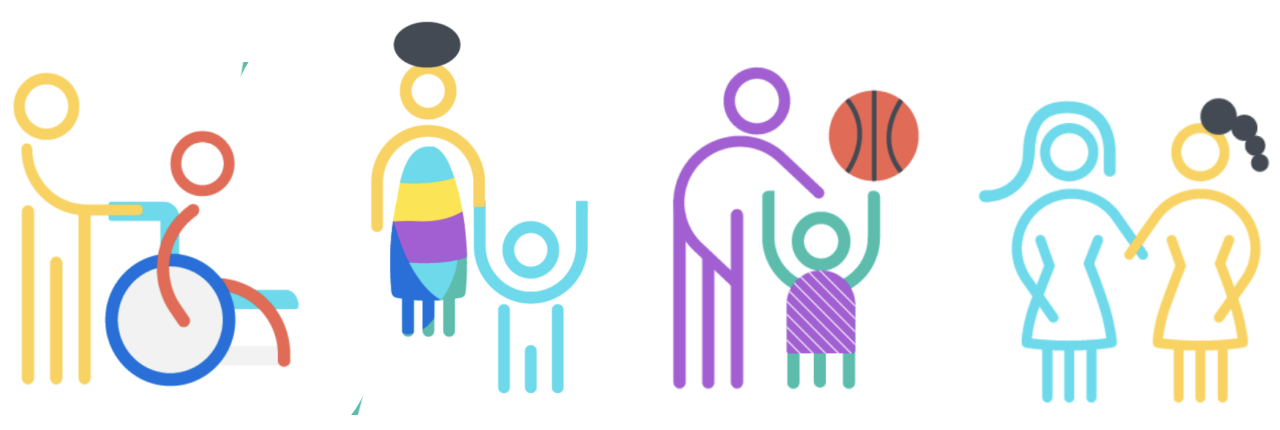
SIMONS SEARCHLIGHT

Voice

of the

Community

OCNDS/CSNK2A1



Data in this report are from **26 participants** with Okur-Chung Syndrome (OCNDS), a change in the CSNK2A1 gene.
18 females and **8** males are represented.

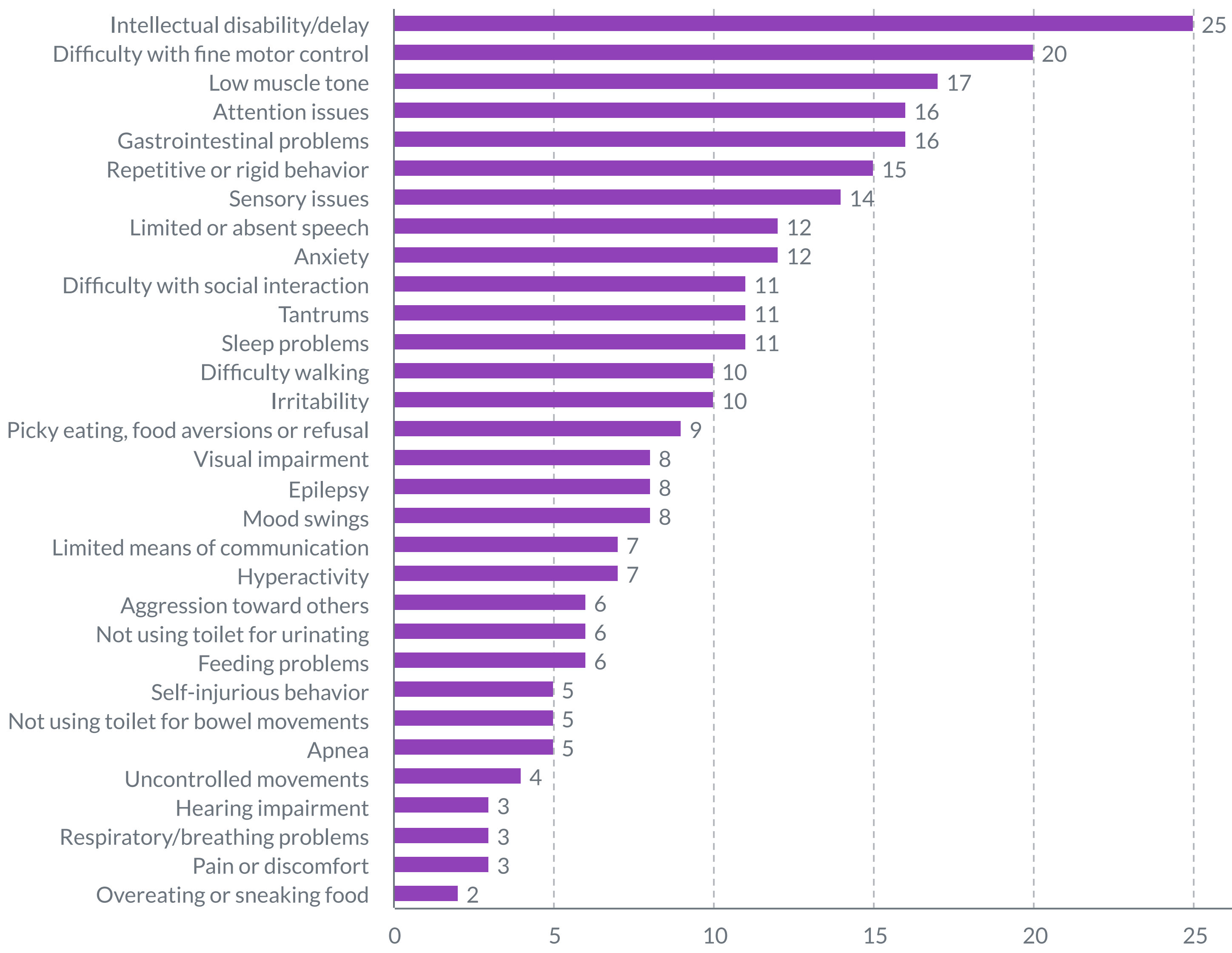
Participants were between **2 and 20** years old.
The average age was **9** years.

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.

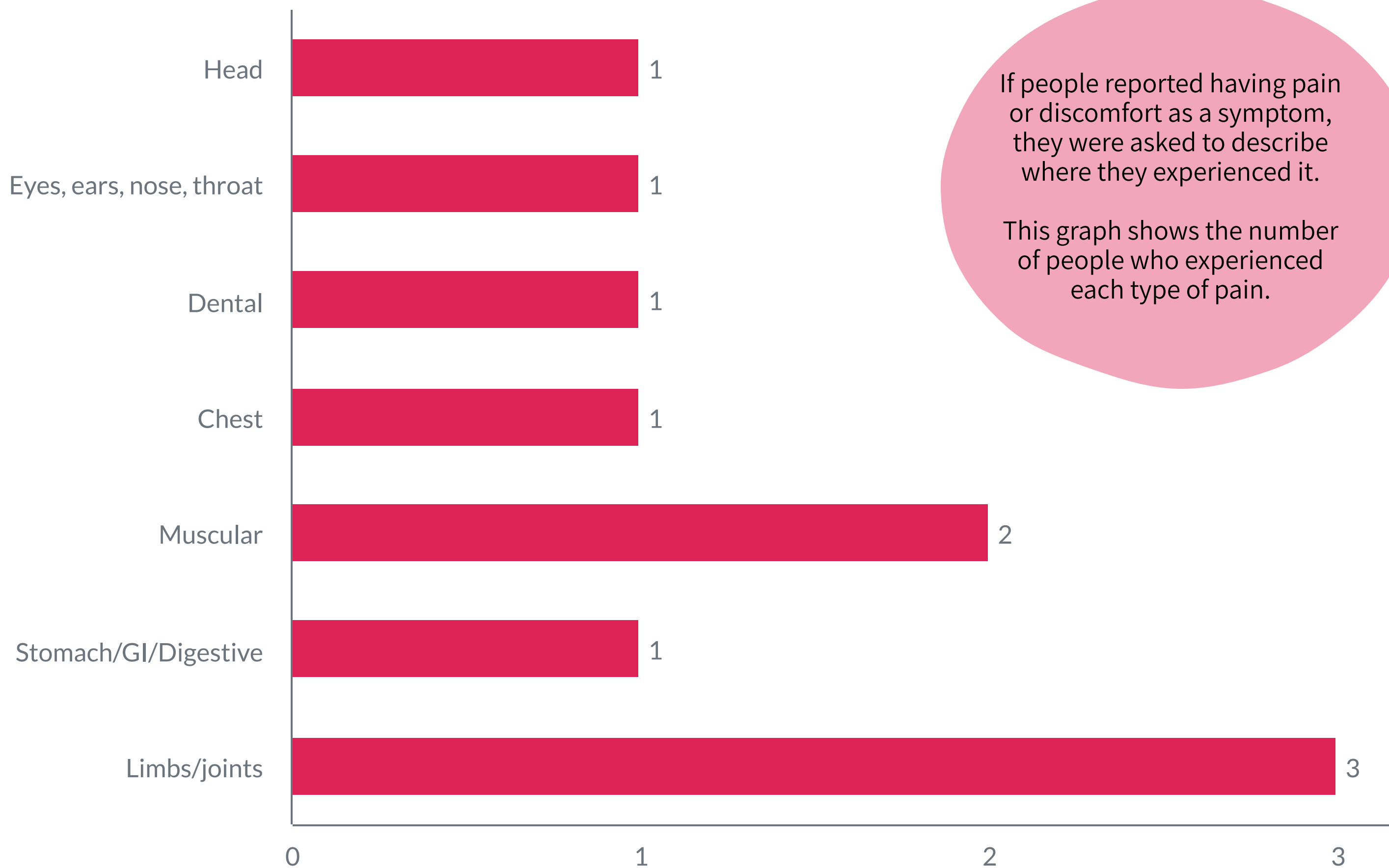
Symptoms Reported for People with OCNDS

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



Note: People may be shown in more than one bar if they reported multiple symptoms.

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 OCNDS. Below, we show the 3 symptoms that were reported to have the most impact.

- 1 Intellectual disability / delay
- 2 Limited or absent speech
- 3 Sleep



Note: People may be shown in more than one category if they reported more than one type of pain.

Symptoms with a High or Very High Impact

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

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

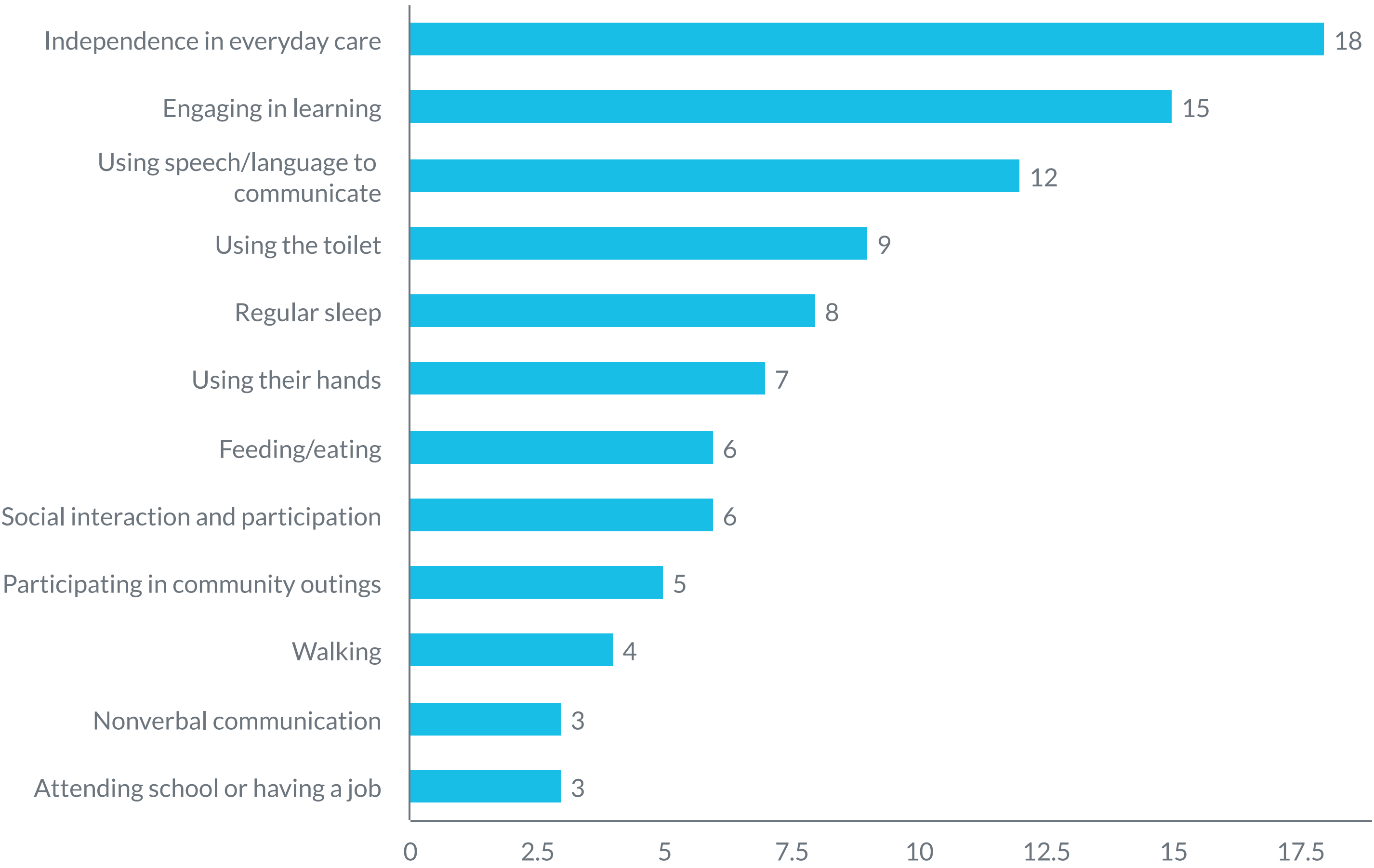
Intellectual disability, developmental delays, or learning delays	21
Attention issues	10
Sleep problems (getting to sleep or staying asleep)	9
Limited or absent speech	8
Anxiety	8
Sensory issues	7
Difficulty with fine motor control	7
Repetitive or rigid behaviors	6
Difficulty with social interaction	6
Picky eating, food aversions or refusal	6
Limited means of communication	5

Notes:

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



Barriers to Participating in Community Outings



If people reported difficulty participating in community outings, they were asked to describe the biggest barrier to participation.

This graph shows the most common barriers to participating in community outings.

Note: People may appear in more than one bar if they reported multiple challenges.

Important Targets for Drug Treatments

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

- 1 Improve learning and cognitive ability
- 2 Improve speech / language
- 3 Improve sleep



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!

