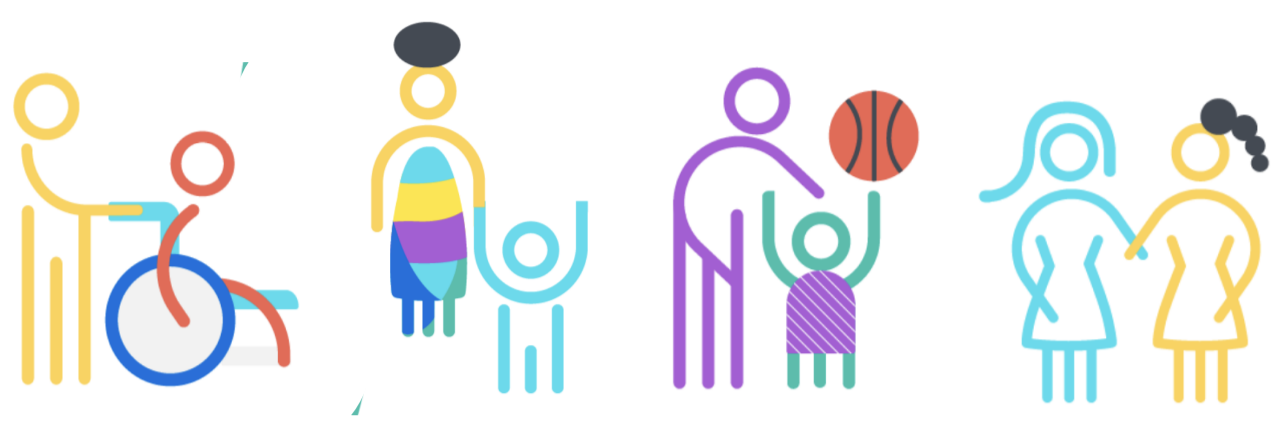


SIMONS SEARCHLIGHT
Voice of the **Community**
 SETBP1



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

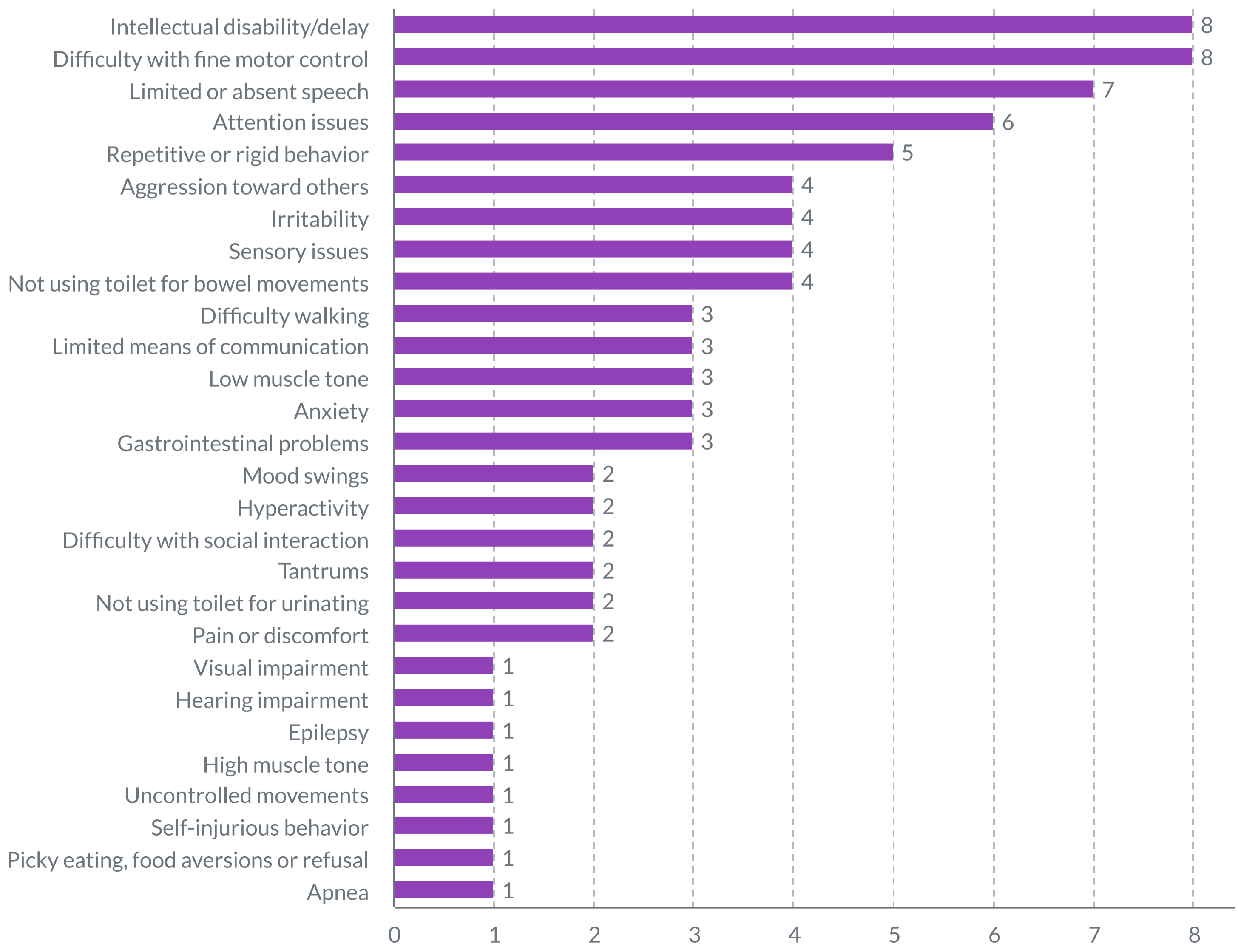
Researchers use Voice of the Community surveys to help inform assessment and treatment decisions from a patient-centered approach.

Data in this report are from **9 participants** with SETBP1.
2 females and **7** males are represented.

Participants were between **3 and 20** years old.
 The average age was **9** years.

Symptoms Reported for People with SETBP1

Caregivers were asked to report all the current symptoms experienced by their family members with SETBP1. 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



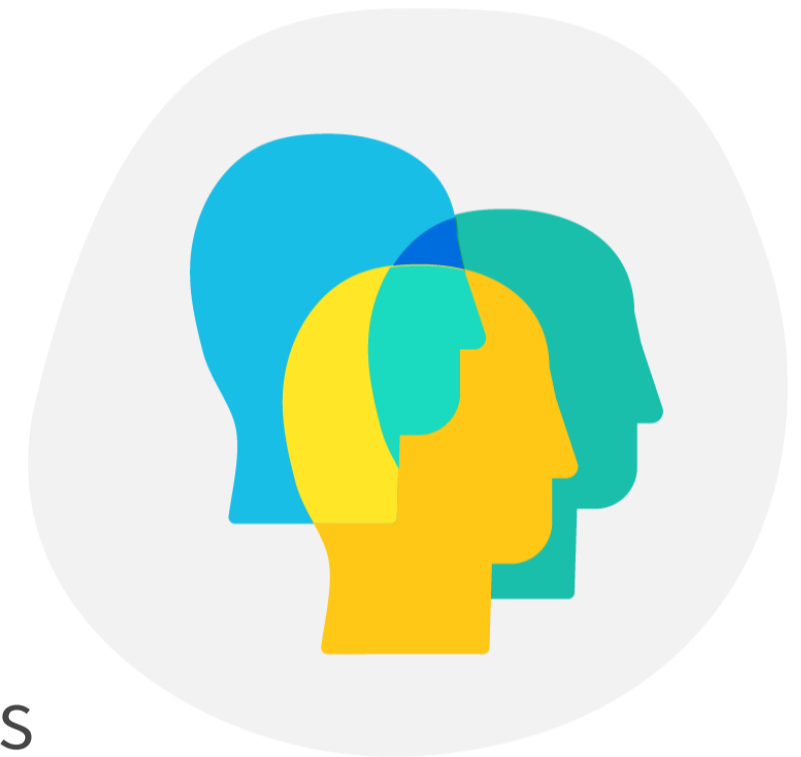
If people reported having pain or discomfort as a symptom, they were asked to describe where they experienced it.

This graph shows the number of people who experienced each type of pain.

Symptoms with the Greatest Impact

Caregivers were asked to rank 3 symptoms that have the most impact on them or their family members with SETBP1. Below, we show the 3 symptoms that were reported to have the most impact.

- 1 Intellectual disability / delay
- 2 Limited or absent speech
- 3 Aggression toward others



Symptoms with a High or Very High Impact

Caregivers were asked to rate the impact for every symptom experienced by their family members with SETBP1. They rated the impact for each symptom from 'no impact' to 'very high impact.'

This table shows the number of people with SETBP1 who are either highly impacted or very highly impacted by a given symptom.

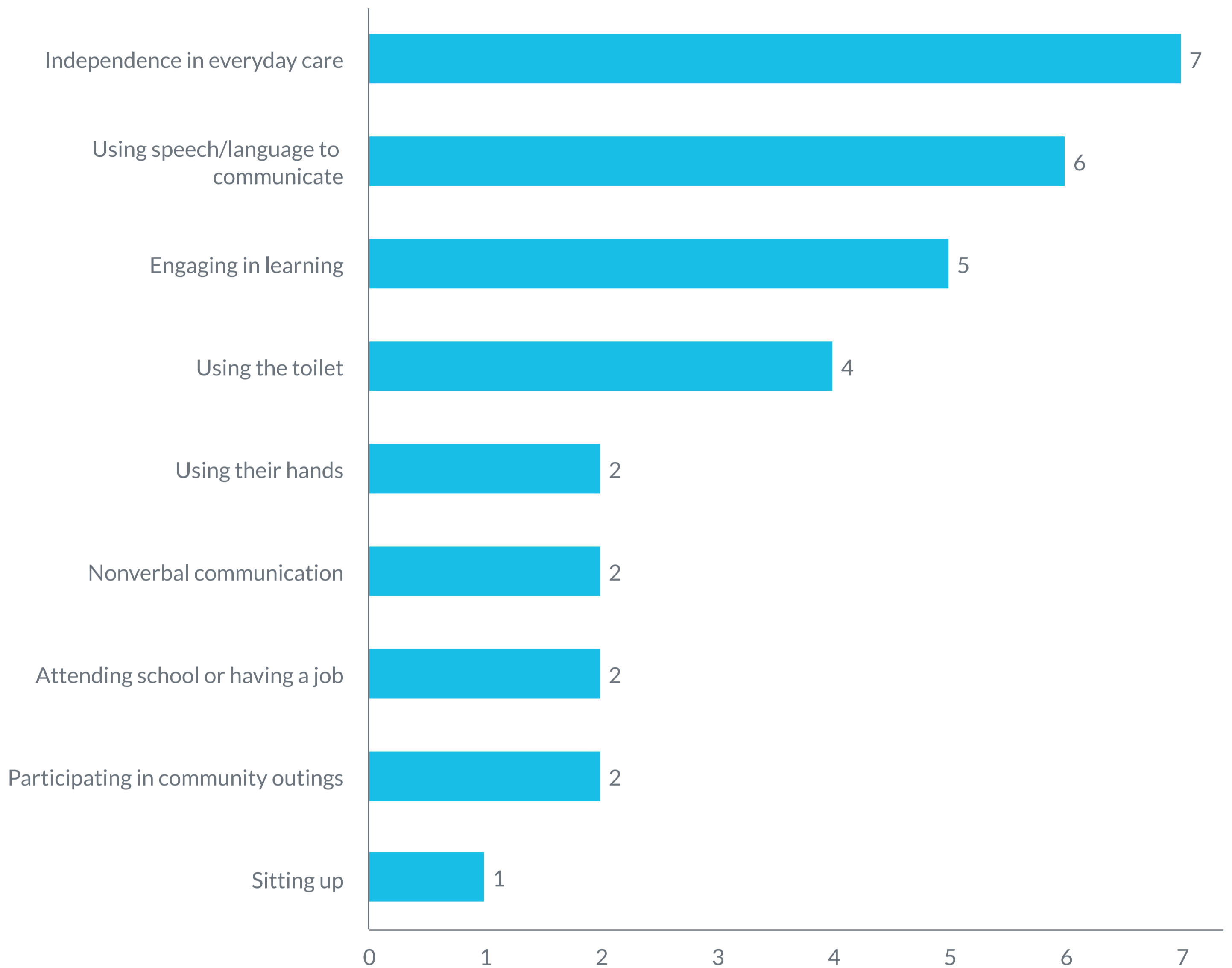
Limited or absent speech	6
Intellectual disability/delays	5
Attention issues	5

Notes:

- People may be shown in more than one row or category 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 SETBP1. Bars in the graph show the number of people with SETBP1 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 SETBP1. This graph shows the 3 treatment targets ranked as most important.

1

Improve learning and cognitive ability

2

Improve speech / language

3

Reduce repetitive or rigid behaviors



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!

