

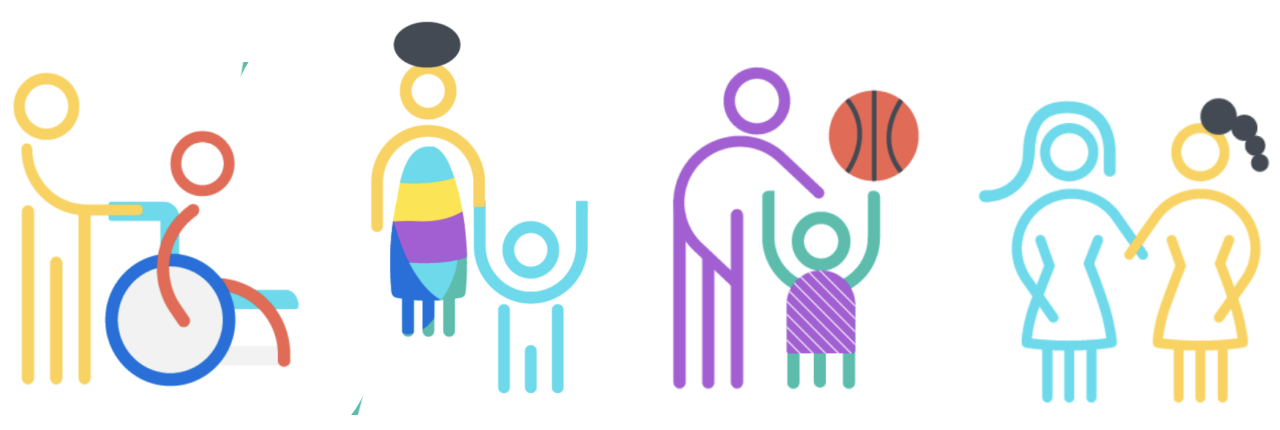
SIMONS SEARCHLIGHT

Voice

of the

Community

MED13L



Data in this report are from **11 participants** with MED13L.
5 females and **6** males are represented.

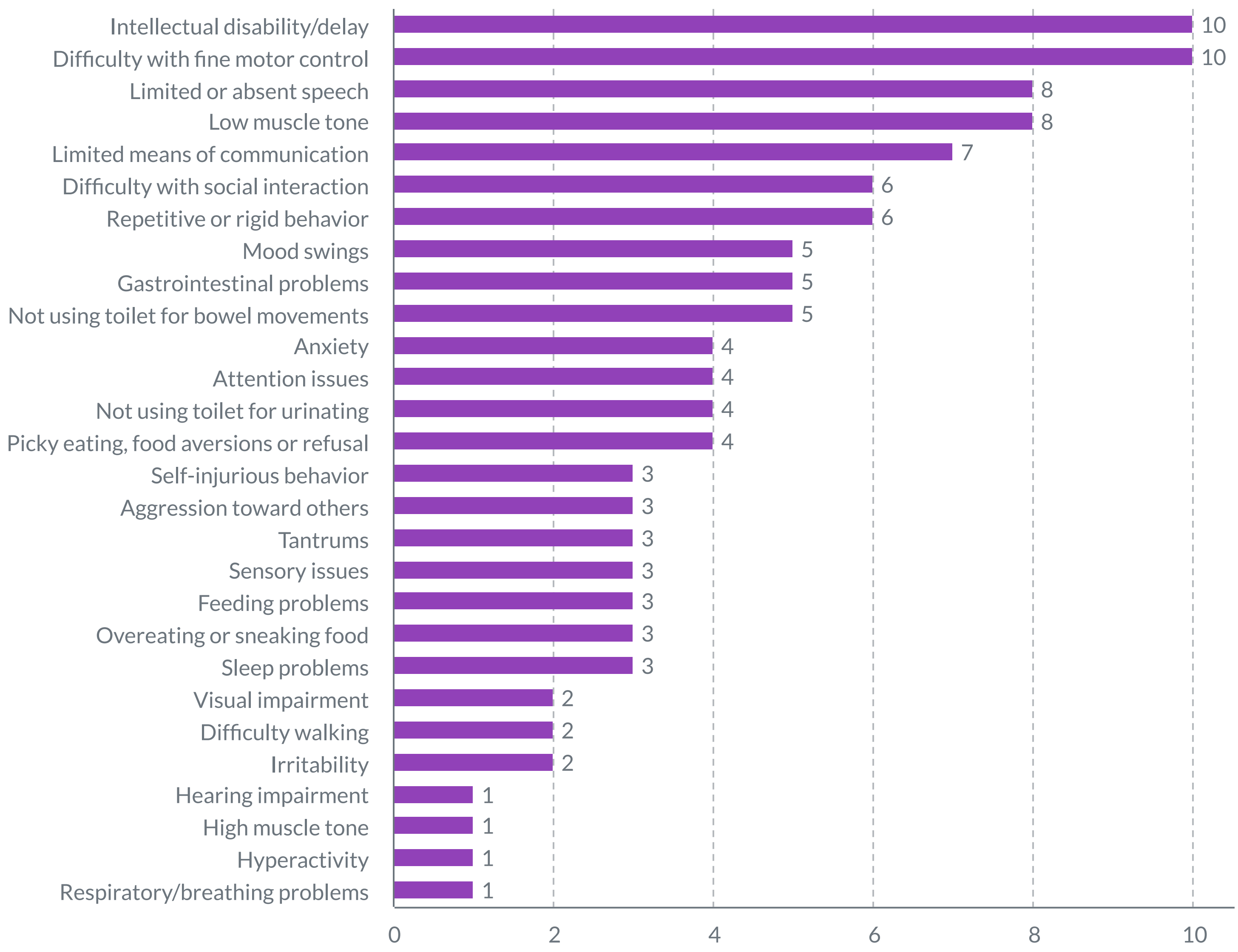
Participants were between **4 and 29** years old.
The average age was **11** years.

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 MED13L

Caregivers were asked to report all the current symptoms experienced by their family members with MED13L. 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.

Symptoms with the Greatest Impact

Caregivers were asked to rank 3 symptoms that have the most impact on them or their family members with MED13L. Below, we show the 3 symptoms that were reported to have the most impact.

1

Limited or absent speech

2

Intellectual disability / delay

3

Anxiety



Symptoms with a High or Very High Impact

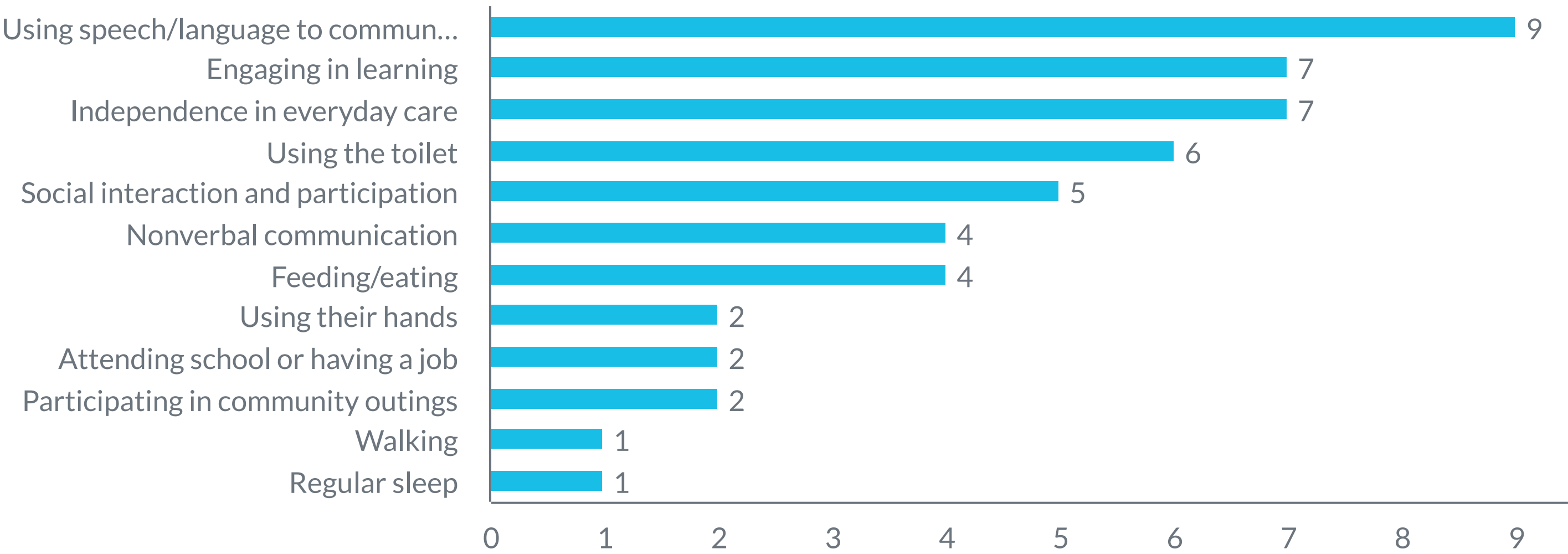
Caregivers were asked to rate the impact for every symptom experienced by their family members with MED13L. They rated the impact for each symptom from 'no impact' to 'very high impact.'

This table shows the number of people with MED13L who are either highly impacted or very highly impacted by a given symptom.

| | |
|--------------------------------|---|
| Intellectual disability/delays | 8 |
| Limited or absent speech | 7 |

Most Challenging Daily Activities

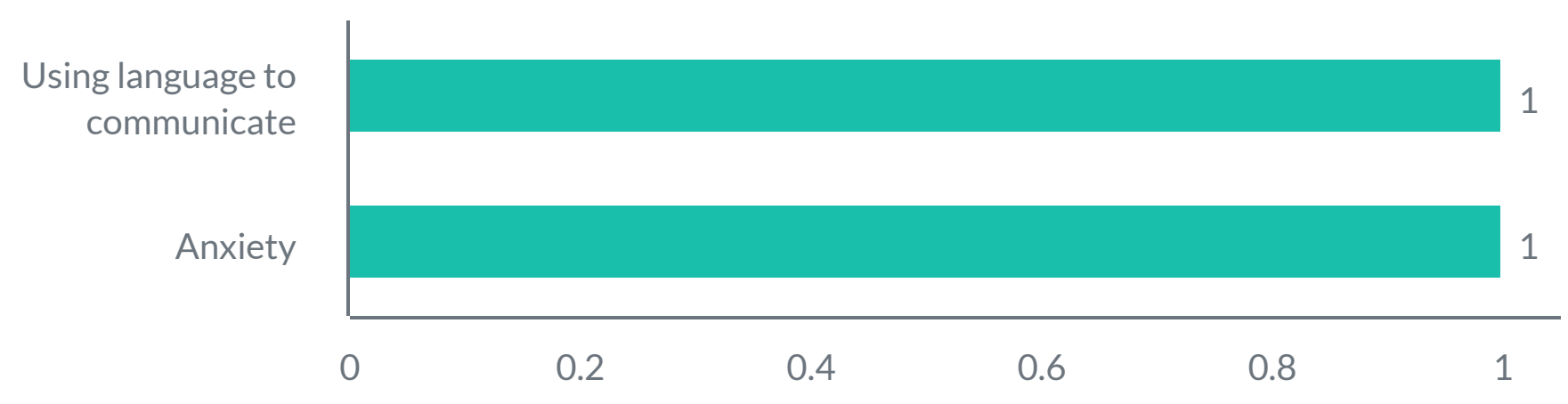
Caregivers selected all the daily activities that are most challenging for their family members with MED13L. Bars in the graph show the number of people with MED13L that have trouble with each daily activity.



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.

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.

Important Targets for Drug Treatments

Caregivers were asked to rank 3 treatment targets that are most important to their family members with MED13L. This graph shows the 3 treatment targets ranked as most important.

- 1 Improve speech / language
- 2 Improve learning and cognition
- 3 Improve behavior



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!

