

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

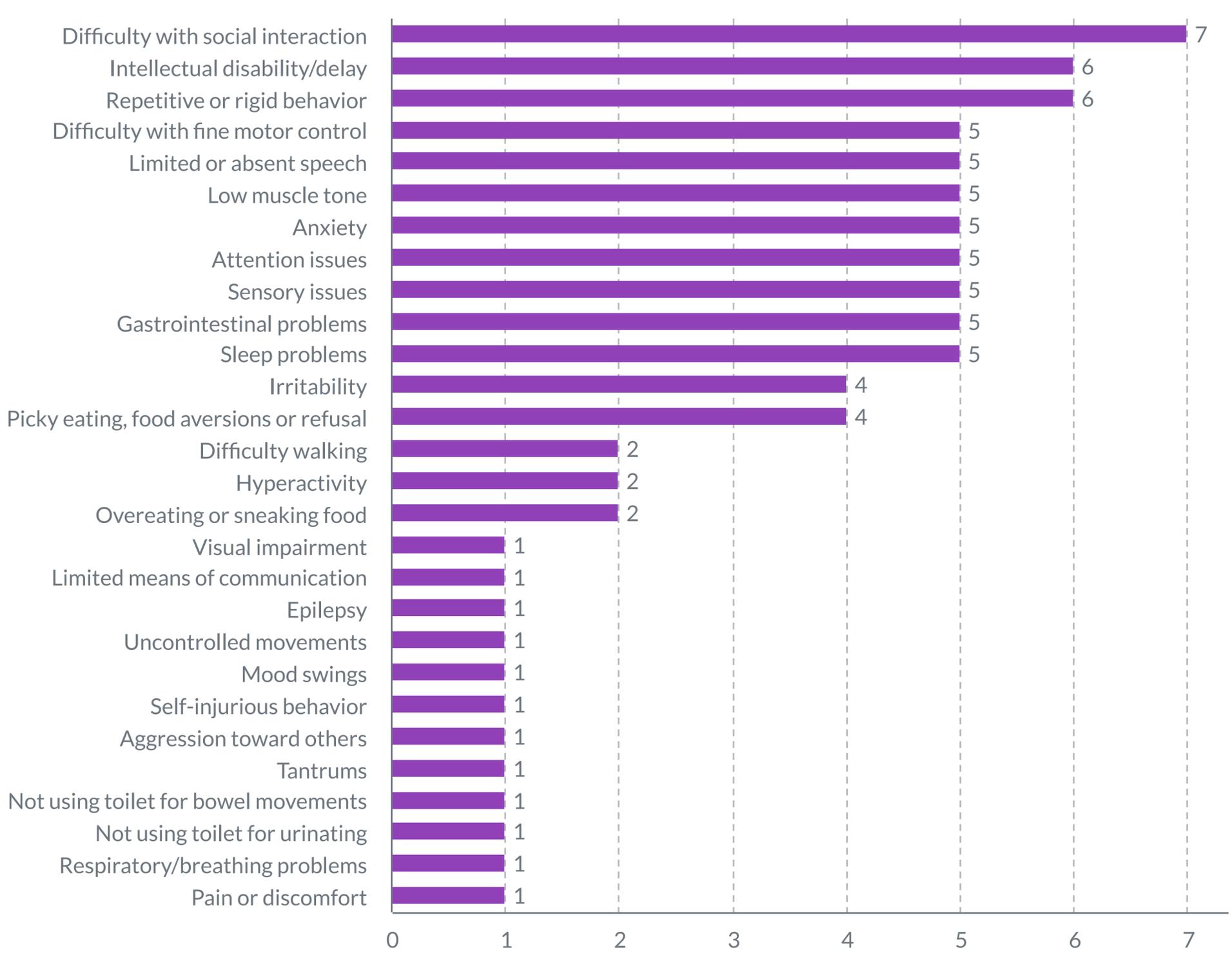
Researchers use Voice of the Community surveys to help inform assessment and treatment decisions from a patient-centered approach.

Data in this report are from **7 participants** with CHD8.
3 females and **4** males are represented.

Participants were between **7 and 19** years old.
 The average age was **10** years.

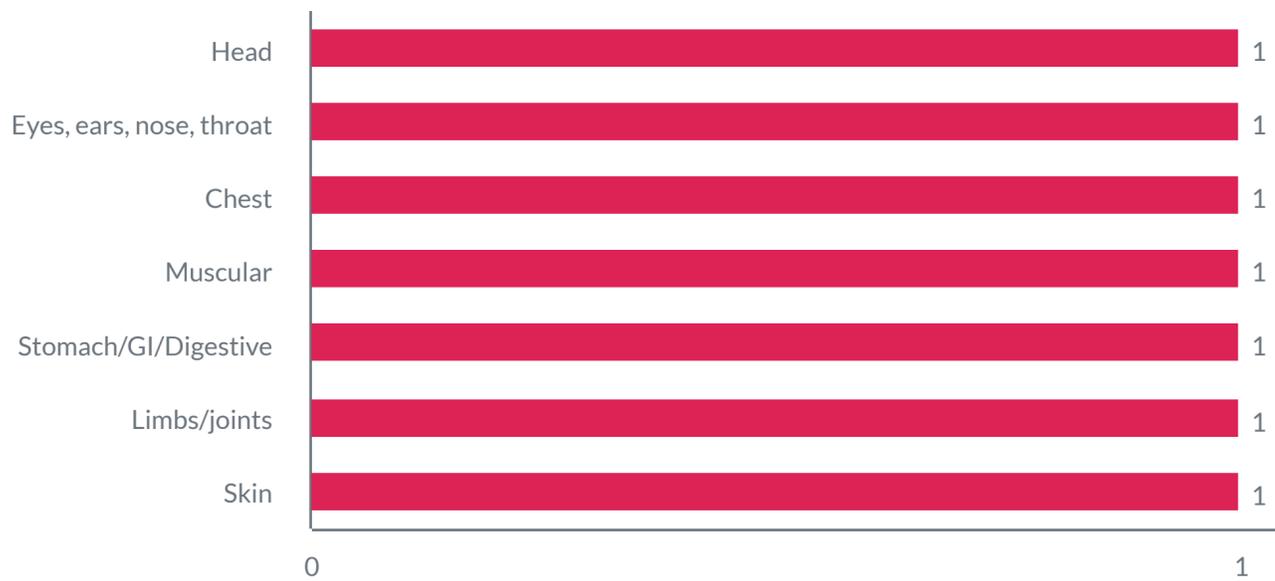
Symptoms Reported for People with CHD8

Caregivers were asked to report all the current symptoms experienced by their family members with CHD8. 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

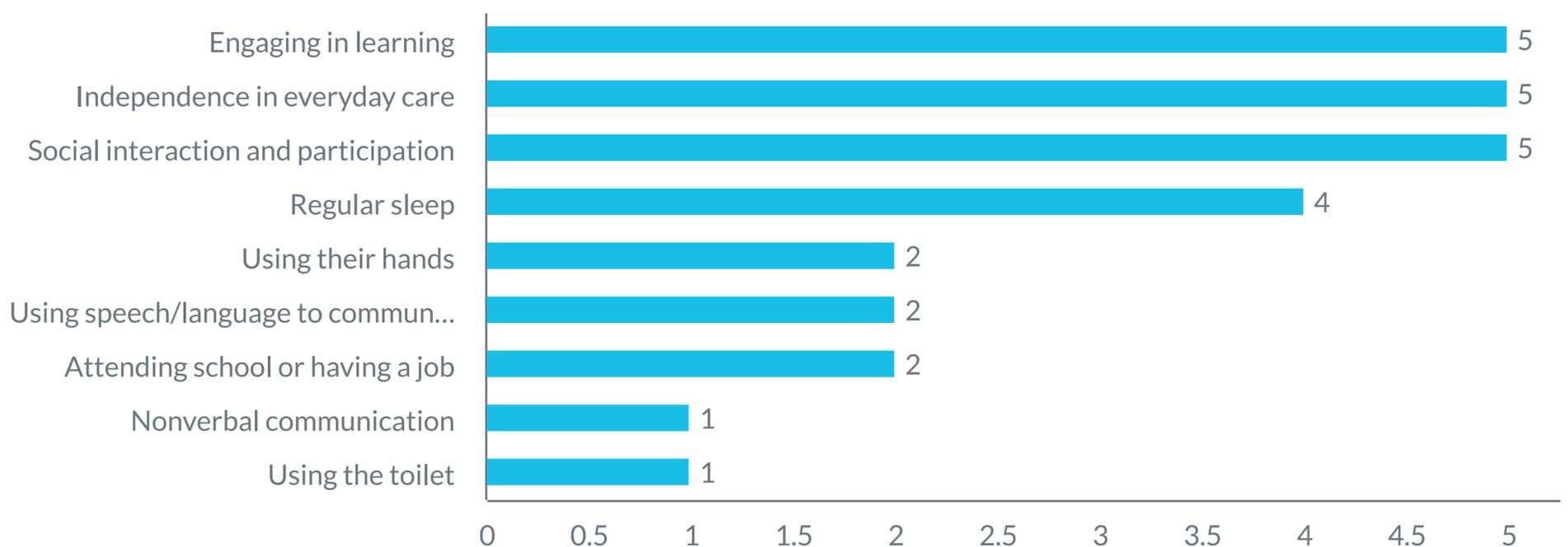
Caregivers were asked to rank 3 symptoms that have the most impact on them or their family members with CHD8. Below, we show the 3 symptoms that were reported to have the most impact.

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



Most Challenging Daily Activities

Caregivers selected all the daily activities that are most challenging for their family members with CHD8. Bars in the graph show the number of people with CHD8 that have trouble with each daily activity.



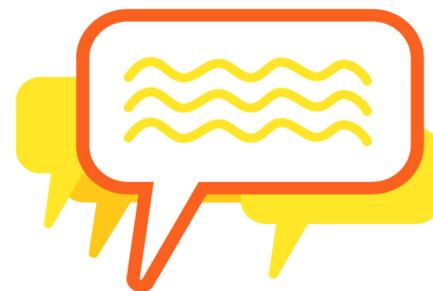
Note: People may be shown in more than one row if they reported multiple symptoms.

Important Targets for Drug Treatments

Caregivers were asked to rank 3 treatment targets that are most important to their family members with CHD8. This graph shows the 3 treatment targets ranked as most important.

1

Improve sleep



2

Improve learning and cognitive ability

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!

