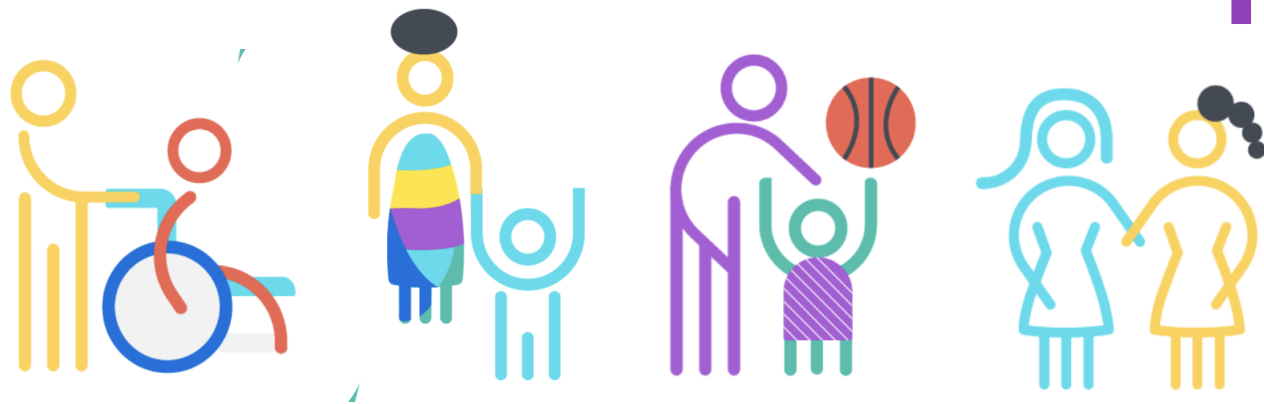




Simons Searchlight Voice of the Community

16p11.2 distal duplication



Data in this report are from **9 participants** with a 16p11.2 distal duplication.

4 females and **5** males are represented.

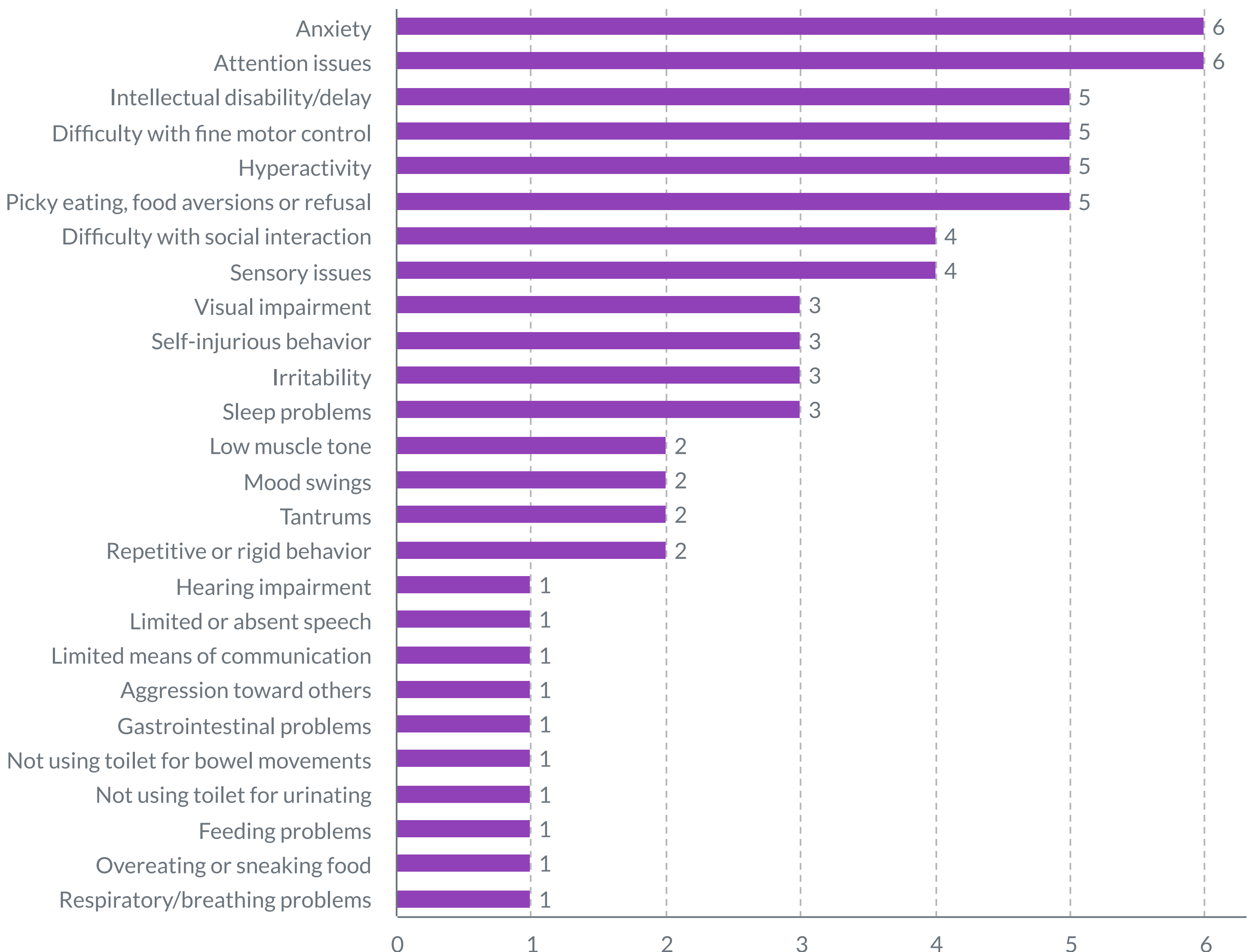
Participants were between **5 and 16** years old.
The average age was **11** years.

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 a 16p11.2 Distal Duplication

Caregivers were asked to report all the current symptoms experienced by their family members with a 16p11.2 distal duplication. 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 a 16p11.2 distal duplication. Below, we show the 3 symptoms that were reported to have the most impact.

1

Attention issues

2

Picky eating

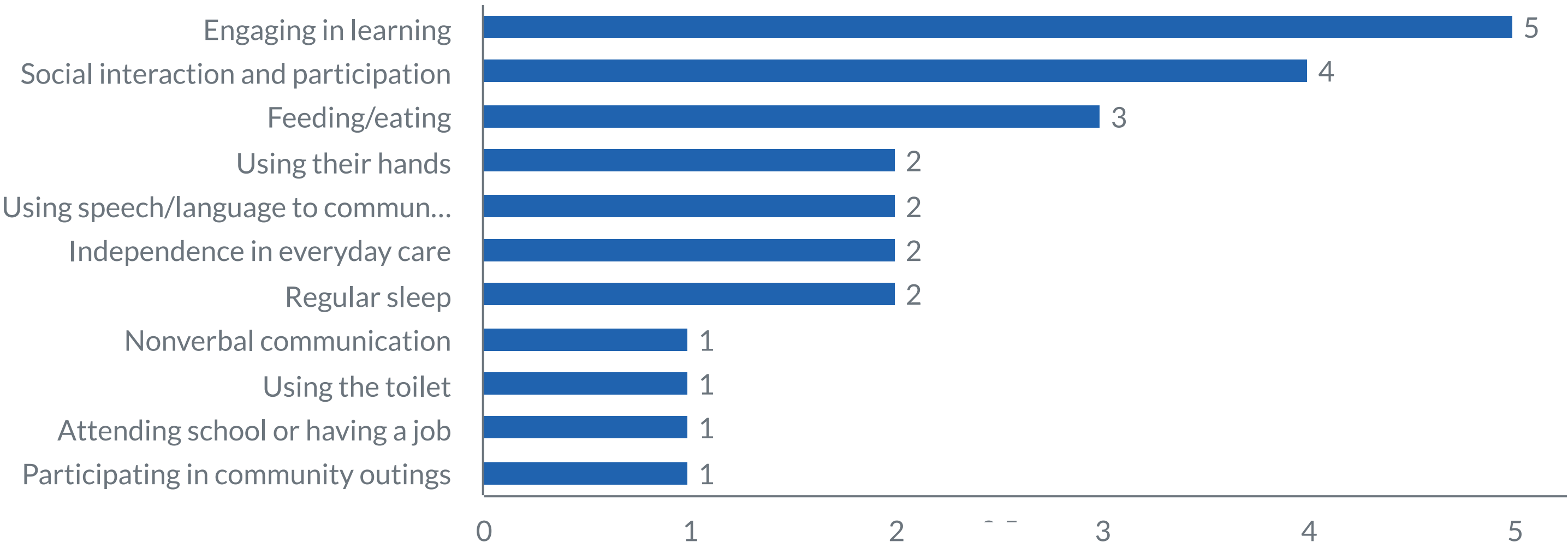
3

Anxiety



Most Challenging Daily Activities

Caregivers selected all the daily activities that are most challenging for their family members with a 16p11.2 distal duplication. Bars in the graph show the those 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 be shown in more than one category if they reported more than one type of pain.

Important Targets for Drug Treatments

Caregivers were asked to rank 3 treatment targets that are most important to their family members with a 16p11.2 distal duplication. This graph shows the 3 treatment targets ranked as most important.

1

Improve learning and cognitive ability

2

Improve mood, irritability, or anxiety

3

Improve eating or feeding



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!

