

SIMONS SEARCHLIGHT
Voice of the **Community**

16p11.2 Distal Deletion



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.

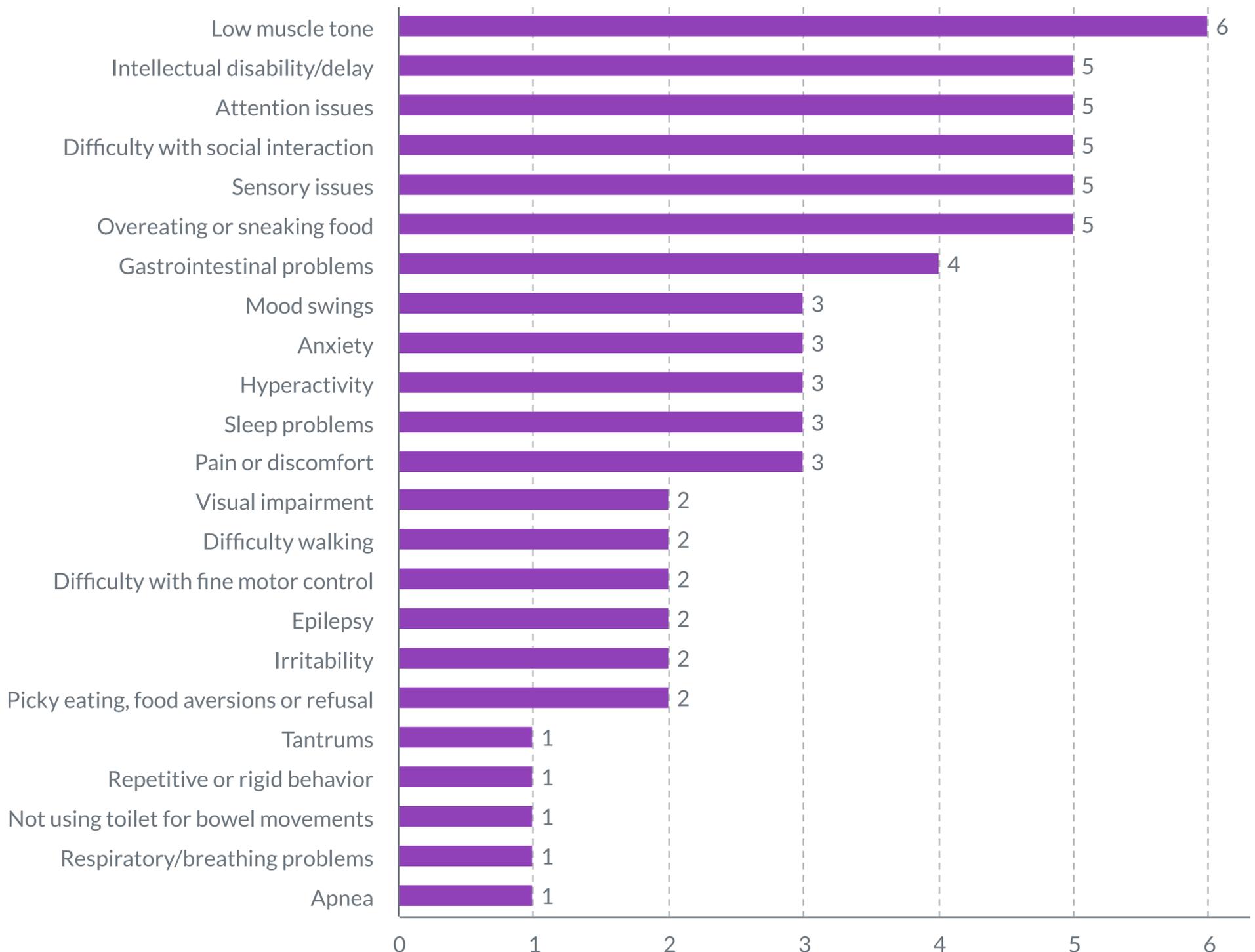
Data in this report are from **7 participants** with a 16p11.2 distal deletion.

4 females and **3** males are represented.

Participants were between **8 and 13** years old.
 The average age was **10** years.

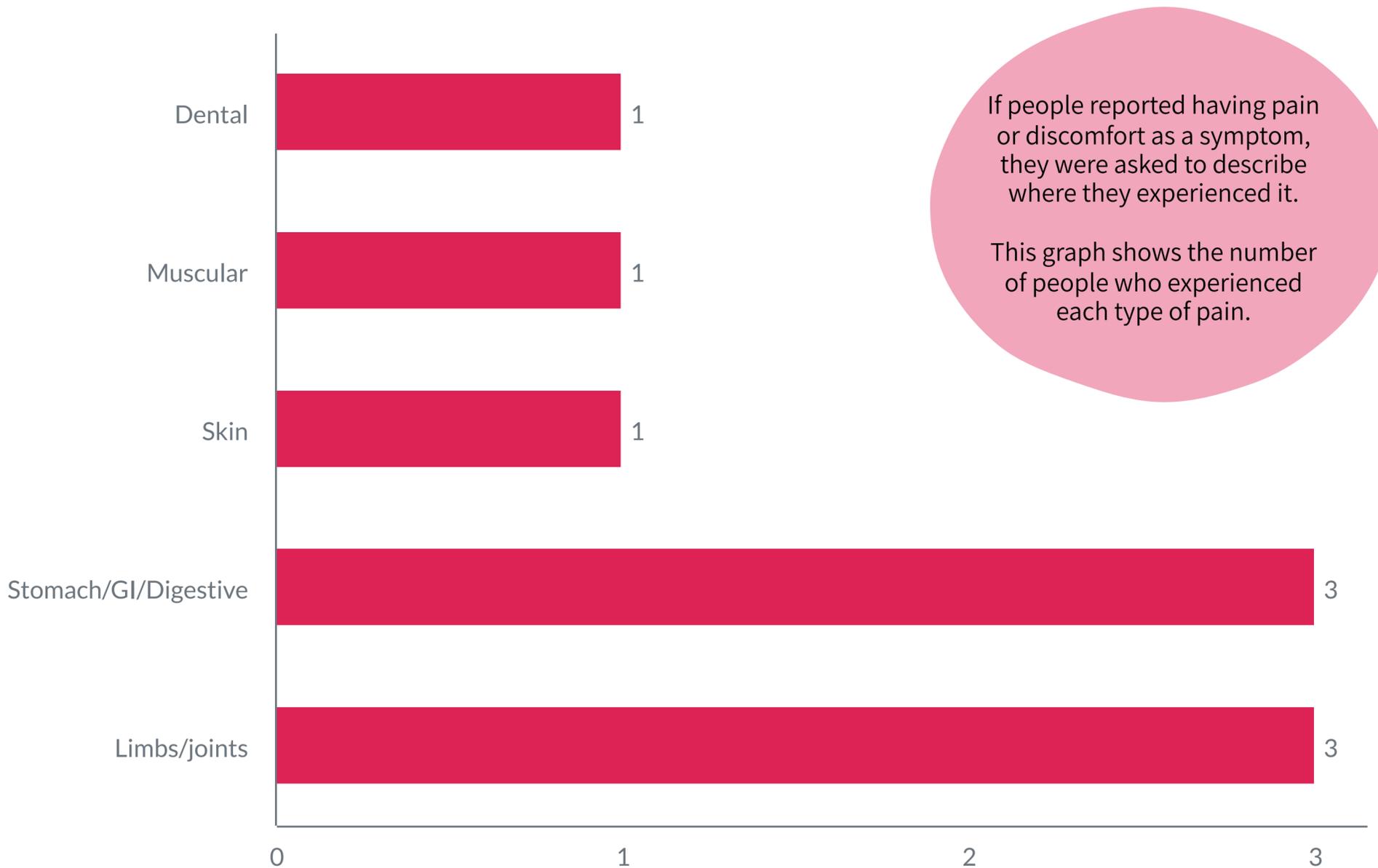
Symptoms Reported for People with a 16p11.2 distal deletion

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

1

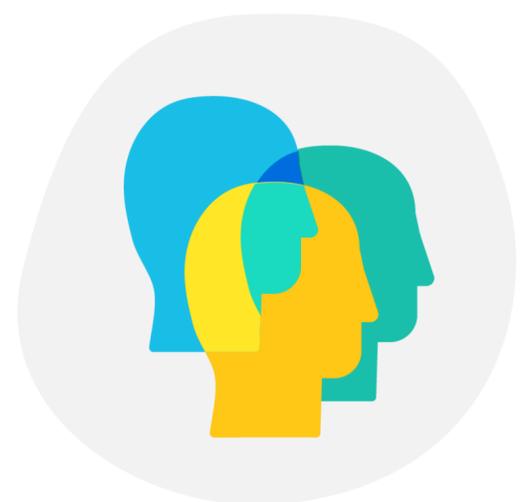
Intellectual disability / delay

2

Attention issues

3

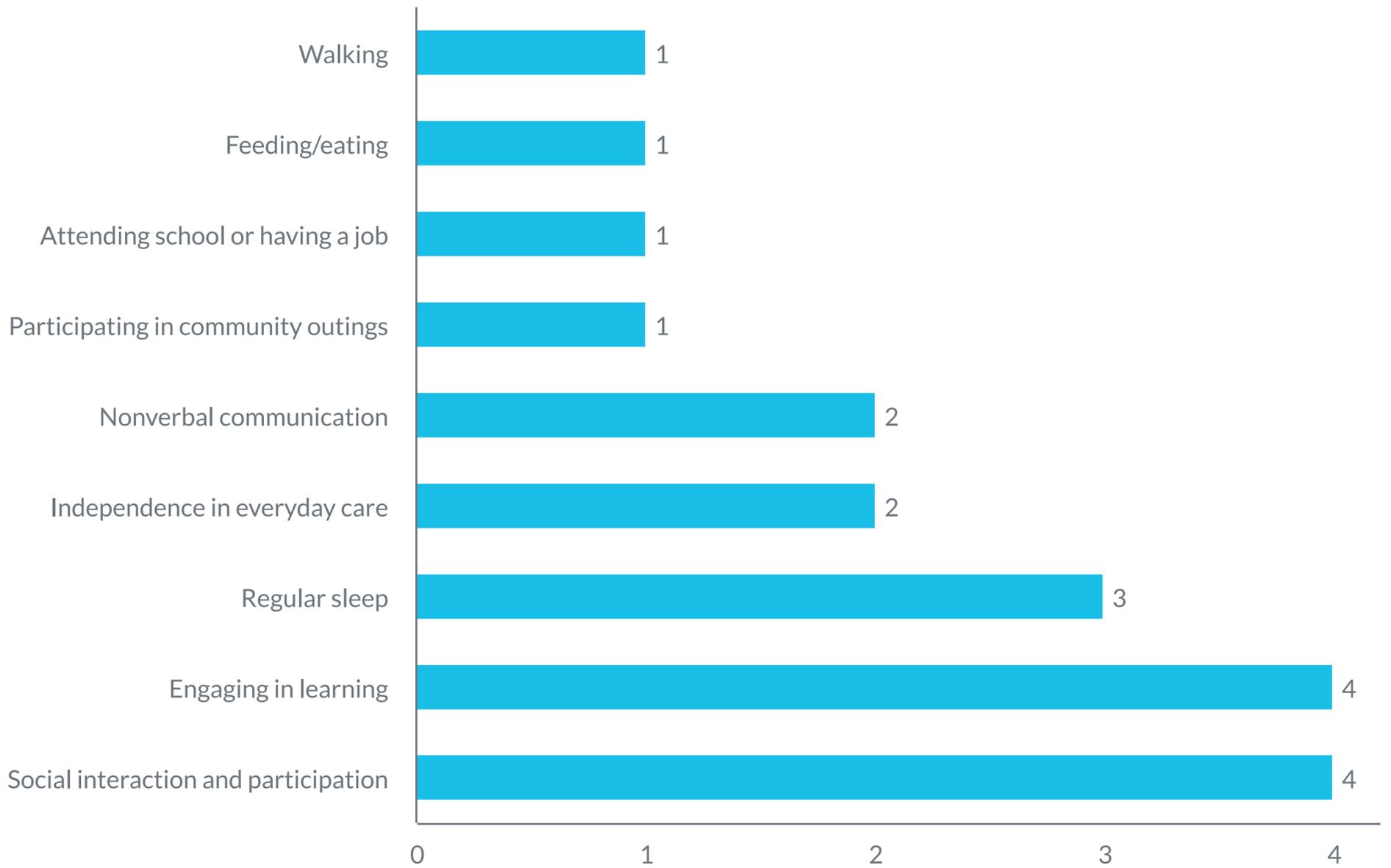
Difficulty with social interaction



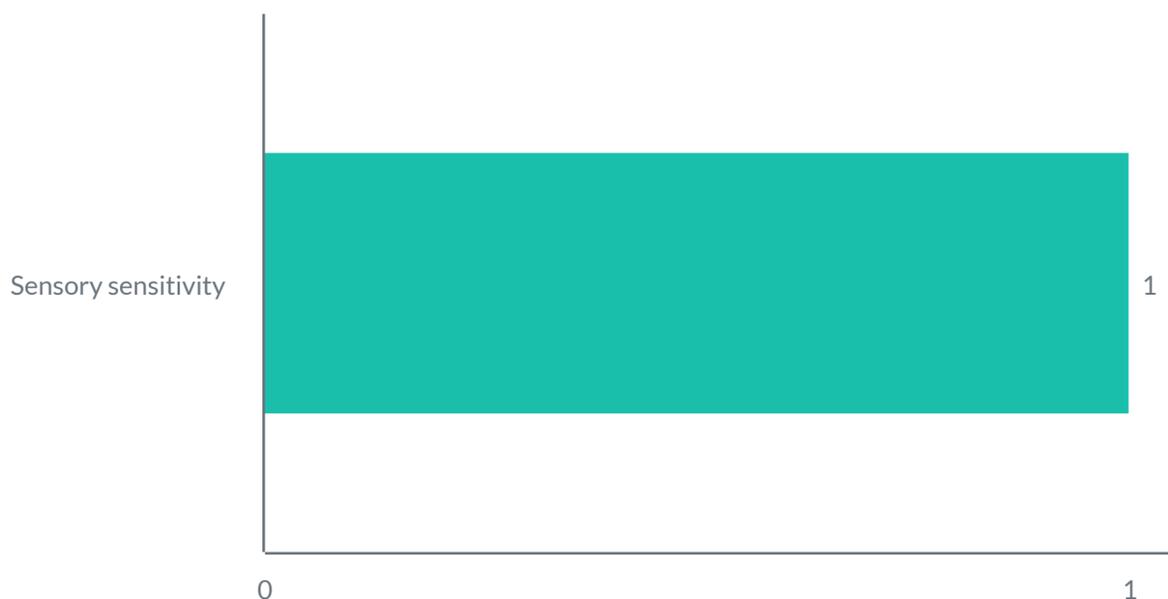
Note: People may be shown in more than one category if they reported more than one type of pain.

Most Challenging Daily Activities

Caregivers selected all the daily activities that are most challenging for their family members with a 16p11.2 distal deletion. Bars in the graph show the number of people with 16p11.2 distal deletion 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 a 16p11.2 distal deletion. This graph shows the 3 treatment targets ranked as most important.

1

Improve learning and cognitive ability

2

Improve eating or feeding

3

Improve social abilities



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!

