Data in this report are from **72 participants** with a 16p11.2 deletion. **28 females** and **44 males** are represented.

Participants were between **6 months** and **25 years old**. The average age was **12 years**.

### Symptoms Reported for People with a 16p11.2 Deletion

Caregivers were asked to report all the current symptoms experienced by their family members with a 16p11.2 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.
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.

**Type of Pain or Discomfort**

- Chest: 1
- Skin: 1
- Eyes, ears, nose, throat: 1
- Muscular: 2
- Head: 3
- Stomach / GI: 4
- Limbs / joints: 7

**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 deletion. Below, we show the 3 symptoms that were reported to have the most impact.

1. Intellectual disability / delay
2. Limited or absent speech
3. Overeating or sneaking food

Note: People may be shown in more than one category if they reported more than one type of pain.
Symptoms with a High or Very High Impact

Caregivers were asked to rate the impact for every symptom experienced by their family members with a 16p11.2 deletion. They rated the impact for each symptom from 'no impact' to 'very high impact.'

This table shows the number of people with a 16p11.2 deletion who are either highly impacted or very highly impacted by a given symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>People</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability / delay</td>
<td>26</td>
</tr>
<tr>
<td>Limited or absent speech</td>
<td>17</td>
</tr>
<tr>
<td>Difficulty with social interaction</td>
<td>16</td>
</tr>
<tr>
<td>Overeating or sneaking food</td>
<td>15</td>
</tr>
<tr>
<td>Attention issues</td>
<td>12</td>
</tr>
<tr>
<td>Anxiety</td>
<td>11</td>
</tr>
<tr>
<td>Sensory issues</td>
<td>10</td>
</tr>
<tr>
<td>Low muscle tone</td>
<td>9</td>
</tr>
<tr>
<td>Gastrointestinal problems</td>
<td>7</td>
</tr>
<tr>
<td>Difficulty with fine motor control</td>
<td>6</td>
</tr>
<tr>
<td>Limited means of communication</td>
<td>6</td>
</tr>
<tr>
<td>Repetitive behaviors</td>
<td>6</td>
</tr>
<tr>
<td>Not using the toilet for bowel movements</td>
<td>5</td>
</tr>
<tr>
<td>Picky eating</td>
<td>5</td>
</tr>
</tbody>
</table>

Notes:
- People may be shown in more than one row if they reported multiple symptoms.
- Symptoms that affected at least 5 or more people were included.
Caregivers selected all the daily activities that are most challenging for their family members with a 16p11.2 deletion. Bars in the graph show the number of people with a 16p11.2 deletion that have trouble with each daily activity.

Using speech/language to communicate: 36
Social interaction and participation: 36
Engaging in learning: 33
Independence in daily personal care: 22
Participating in community outings: 16
Attending school or having a job: 12
Using the toilet: 9
Regular sleep: 8
Using their hands: 7
Feeding/eating: 6
Walking: 5
Nonverbal communication: 5

Barriers to Participating in Community Outings

If people reported difficulty participating in community outings, they were asked to describe the biggest barrier to participation.

Sensory sensitivity: 1
Using language to communicate: 2
Behavior: 4
Anxiety: 6

Note: People may appear in more than one bar if they reported multiple challenges.
Caregivers were asked to rank 3 treatment targets that are most important to their family members with a 16p11.2 deletion. This graph shows the 3 treatment targets ranked as most important.

1. Improve learning and cognitive ability
2. Improve speech / language
3. Improve social interaction 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!