Data in this report are from **32 participants** with a 16p11.2 duplication. **15 females and 17 males** are represented.

Participants were between **3 and 32 years old**. The average age was **12 years**.

**Symptoms Reported for People with a 16p11.2 Duplication**

Caregivers were asked to report all the current symptoms experienced by their family members with a 16p11.2 duplication. A list of 32 symptoms was provided. Bars in the graph show the number of people who currently experience the symptom.

- Intellectual disability/delays: 26
- Sensory issues: 22
- Difficulty with social interaction: 21
- Anxiety: 21
- Attention issues: 20
- Sleep problems: 18
- Repetitive behaviors: 17
- Hyperactivity: 16
- Gastrointestinal problems: 16
- Difficulty with fine motor control: 15
- Low muscle tone: 15
- Tantrums: 14
- Mood swings: 13
- Irritability: 13
- Picky eating: 12
- Aggression toward others: 11
- Sum of Self-injurious behavior: 9
- Overeating or sneaking food: 7
- Visual impairment: 7
- Limited or absent speech: 5
- Pain or discomfort: 5
- Epilepsy: 4
- Not using toilet for bowel movements: 4
- Limited means of communication: 3
- High muscle tone: 2
- Difficulty walking: 2
- Uncontrolled movements: 1
- Respiratory/breathing problems: 1
- Not using the toilet for urinating: 1

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.

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

1. **Intellectual disability / delay**
2. **Anxiety**
3. **Attention issues**

*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 duplication. 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 duplication 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/delays</td>
<td>19</td>
</tr>
<tr>
<td>Sensory issues</td>
<td>13</td>
</tr>
<tr>
<td>Anxiety</td>
<td>12</td>
</tr>
<tr>
<td>Difficulty with social interaction</td>
<td>12</td>
</tr>
<tr>
<td>Attention issues</td>
<td>11</td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>11</td>
</tr>
<tr>
<td>Repetitive or rigid behavior</td>
<td>9</td>
</tr>
<tr>
<td>Gastrointestinal problems</td>
<td>8</td>
</tr>
<tr>
<td>Picky eating, food aversions or refusal</td>
<td>8</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>8</td>
</tr>
<tr>
<td>Mood swings</td>
<td>7</td>
</tr>
<tr>
<td>Irritability</td>
<td>7</td>
</tr>
<tr>
<td>Difficulty with fine motor control</td>
<td>6</td>
</tr>
<tr>
<td>Aggression toward others</td>
<td>6</td>
</tr>
<tr>
<td>Tantrums</td>
<td>6</td>
</tr>
<tr>
<td>Limited or absent speech</td>
<td>5</td>
</tr>
<tr>
<td>Overeating or sneaking food</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.
Most Challenging Daily Activities

Caregivers selected all the daily activities that are most challenging for their family members with a 16p11.2 duplication. Bars in the graph show the number of people with a 16p11.2 duplication that have trouble with each daily activity.

- Social interaction and participation: 19
- Independence in daily personal care: 16
- Regular sleep: 14
- Engaging in learning: 13
- Participating in community outings: 9
- Using speech/language to communicate: 8
- Using their hands: 7
- Attending school or having a job: 4
- Nonverbal communication: 3
- Using the toilet: 3
- Feeding/eating: 2

Barriers to Participating in Community Outings

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

- Using language for communication: 1
- Sensory sensitivity: 2
- Anxiety: 2
- Behavior: 4

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 duplication. This graph shows the 3 treatment targets ranked as most important.

1. Improve learning and cognitive ability
2. Improve behavior
3. Improve mood, irritability, or anxiety

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!