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**.

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**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.

- Low muscle tone: 6
- Intellectual disability/delay: 5
- Attention issues: 5
- Difficulty with social interaction: 5
- Sensory issues: 5
- Overeating or sneaking food: 5
- Gastrointestinal problems: 4
- Mood swings: 3
- Anxiety: 3
- Hyperactivity: 3
- Sleep problems: 3
- Pain or discomfort: 3
- Visual impairment: 2
- Difficulty walking: 2
- Difficulty with fine motor control: 2
- Epilepsy: 2
- Irritability: 2
- Picky eating, food aversions or refusal: 2
- Tantrums: 1
- Repetitive or rigid behavior: 1
- Not using toilet for bowel movements: 1
- Respiratory/breathing problems: 1
- Apnea: 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.

### Type of Pain or Discomfort

- **Dental**: 1
- **Muscular**: 1
- **Skin**: 1
- **Stomach/GI/Digestive**: 3
- **Limbs/joints**: 3

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.
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.

**Most Challenging Daily Activities**

- Walking: 1
- Feeding/eating: 1
- Attending school or having a job: 1
- Participating in community outings: 1
- Nonverbal communication: 2
- Independence in everyday care: 2
- Regular sleep: 3
- Engaging in learning: 4
- Social interaction and participation: 4

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.
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!