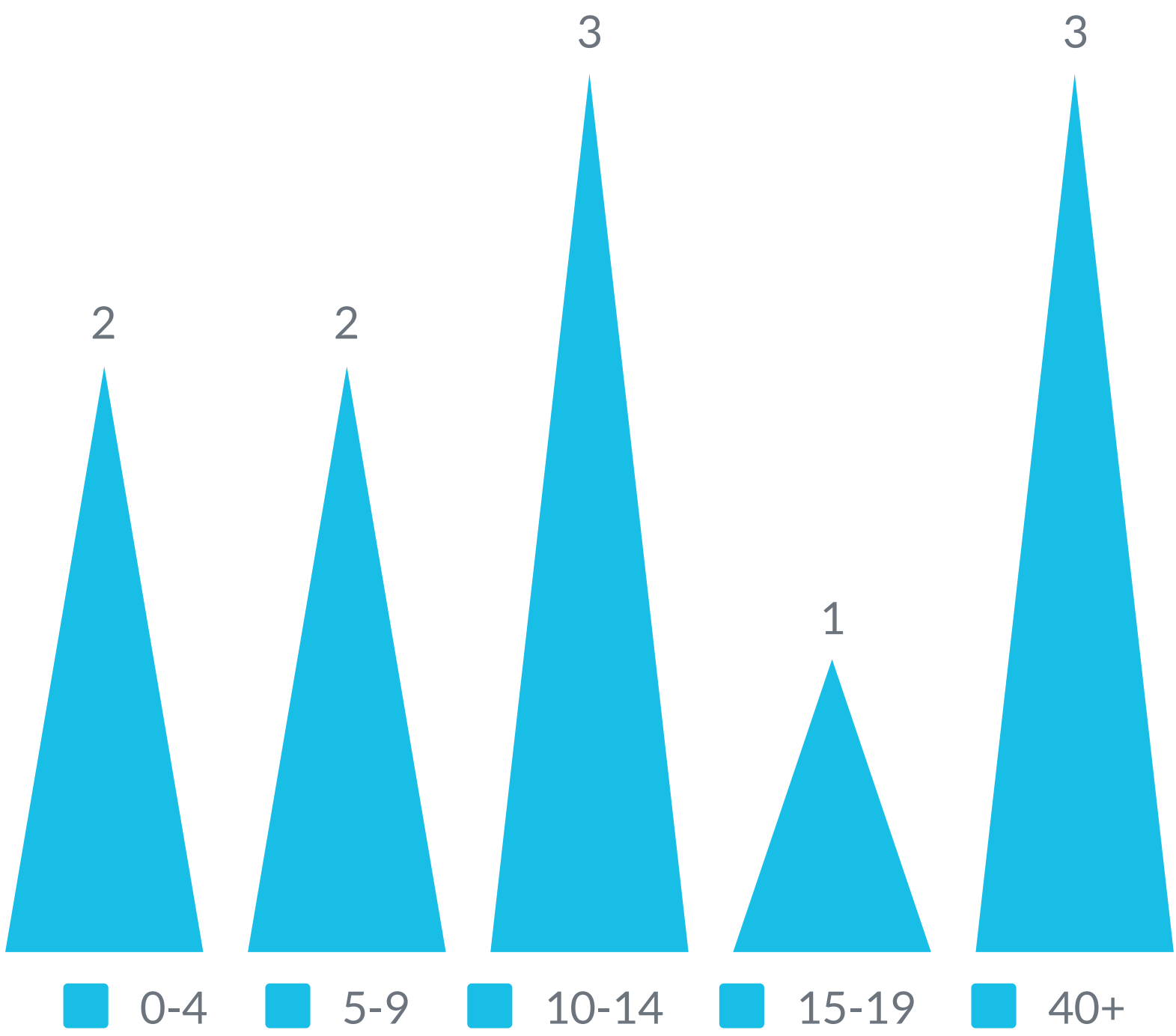


Simons Searchlight Registry Update 16p11.2 Distal Deletion

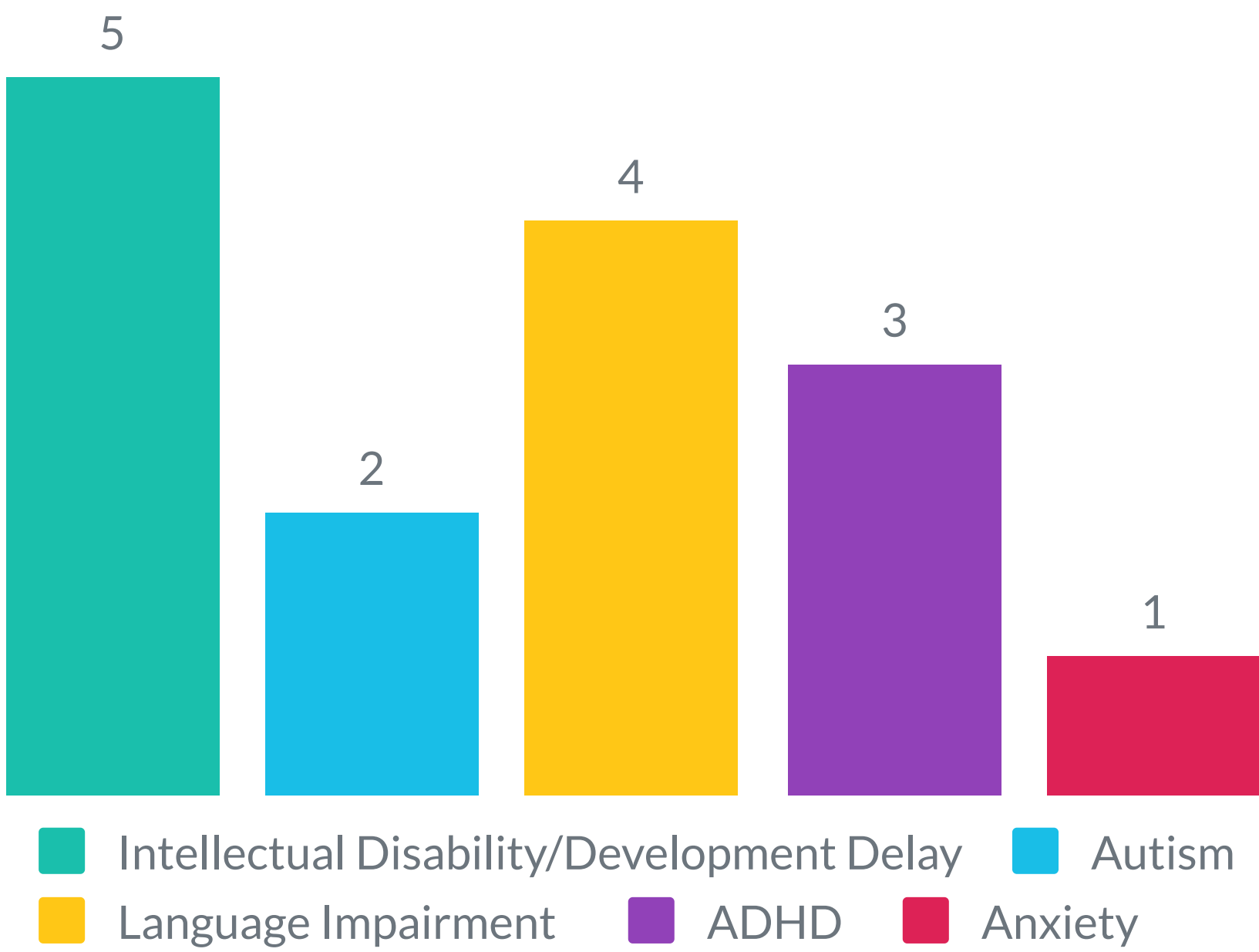
September 2021

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 11 participants with a 16p11.2 distal deletion.

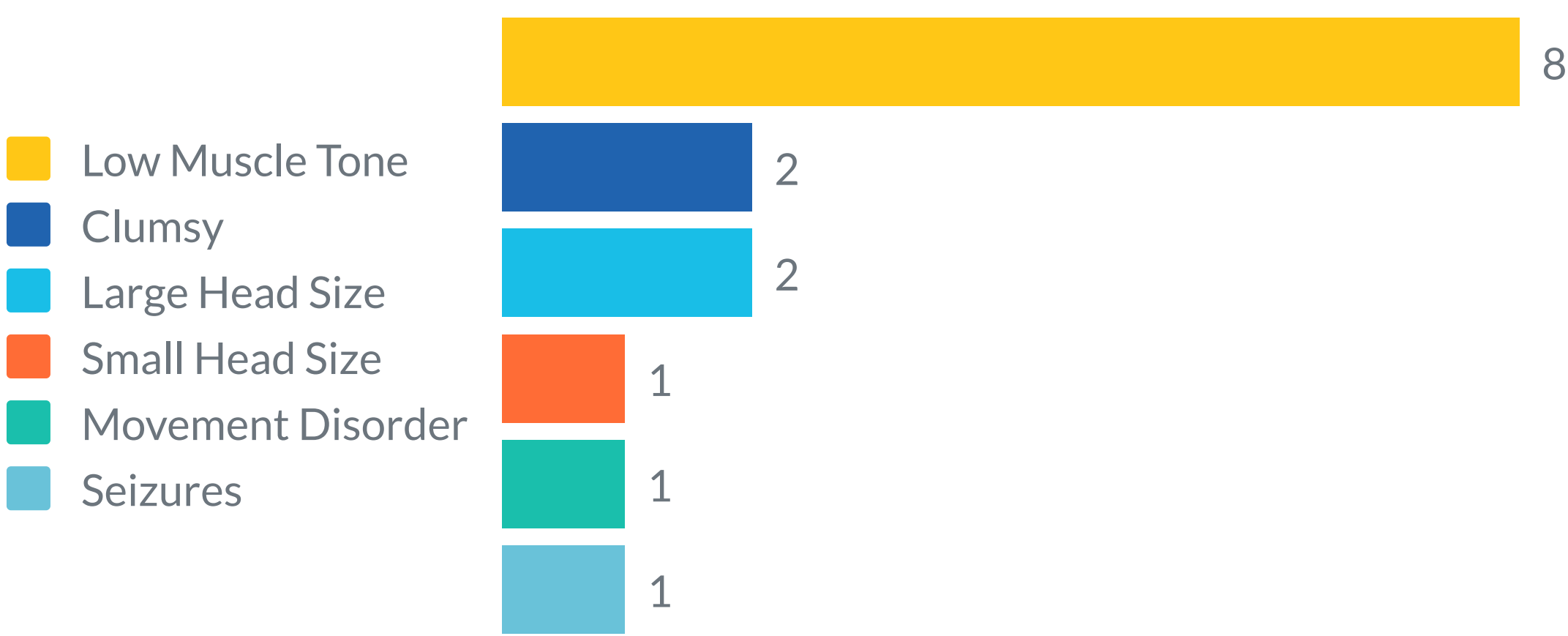
Ages in Years



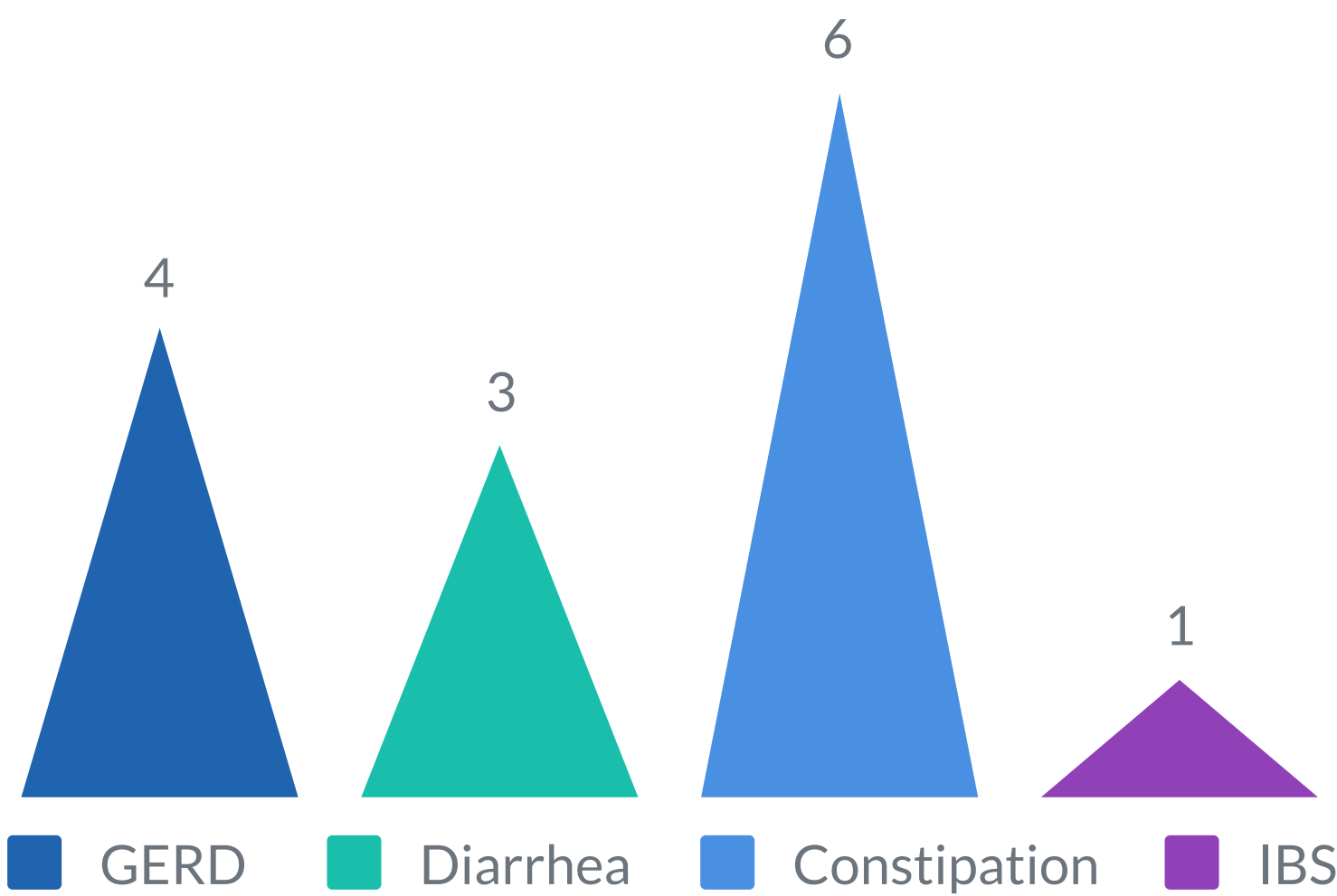
Developmental & Behavioral Diagnoses



Neurological Problems



Gastrointestinal Problems



Notes:

- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Information on reported seizure types is included on the 2021 quarter 1 registry report available on simonssearchlight.org/research/what-we-study/16p11-2-distal-deletion/.

Participation & Registration

The information in this report is made possible by the active participation of the 16p11.2 distal deletion community! Progress for individuals in your community with a 16p11.2 deletion is shown below -- log in to your simonssearchlight.org dashboard today to check for new surveys and tasks. Your data could hold the clues geneticists need to find answers.



Information Spotlight: Sleep Concerns

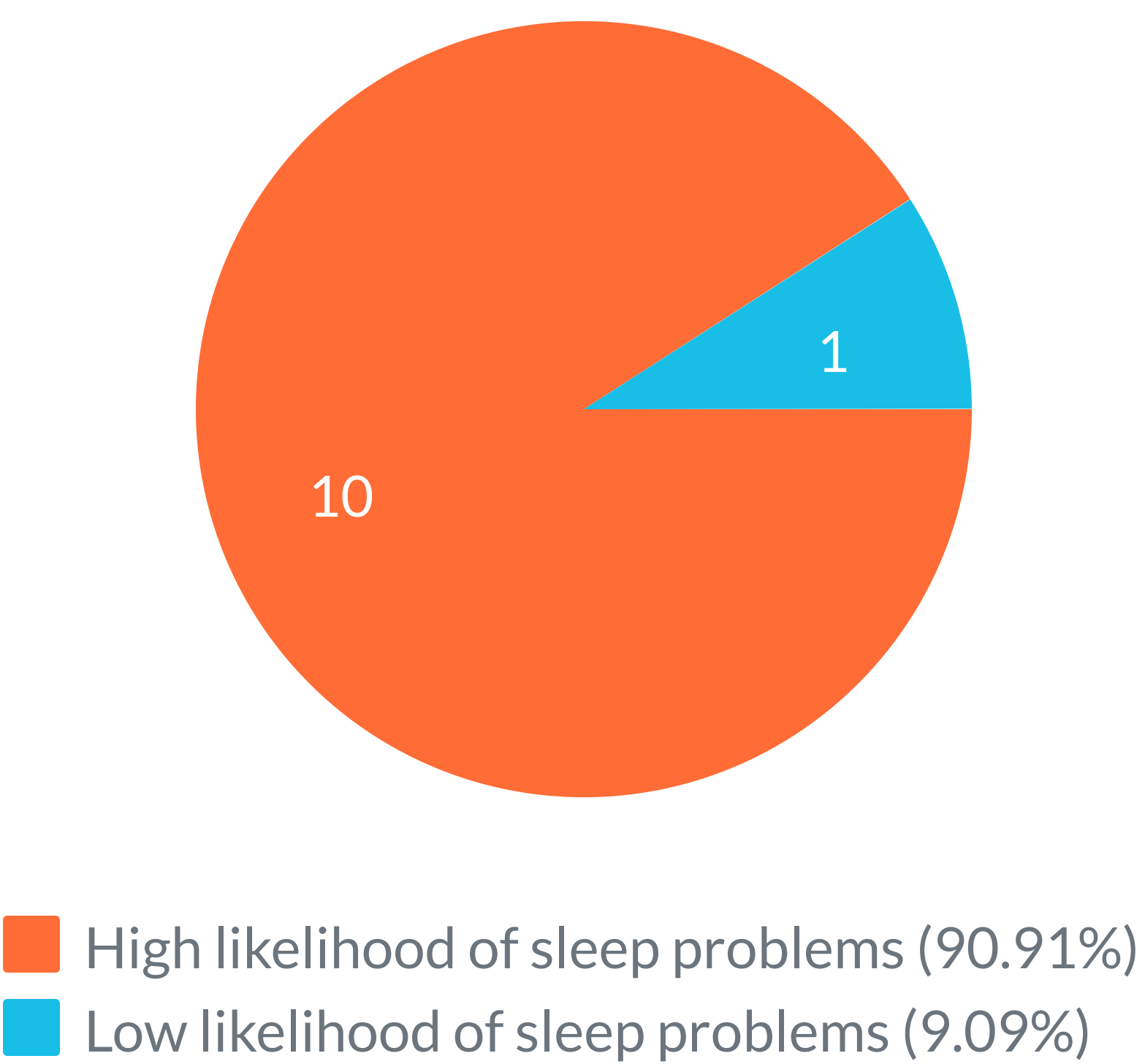
The Children’s Sleep Habits Questionnaire is a survey used to understand sleep habits and possible sleep problems in children. All individuals were between 2 and 18 years of age.

11 children with a 16p11.2 distal deletion are represented.

Top Sleep Problems in children with a 16p11.2 distal deletion



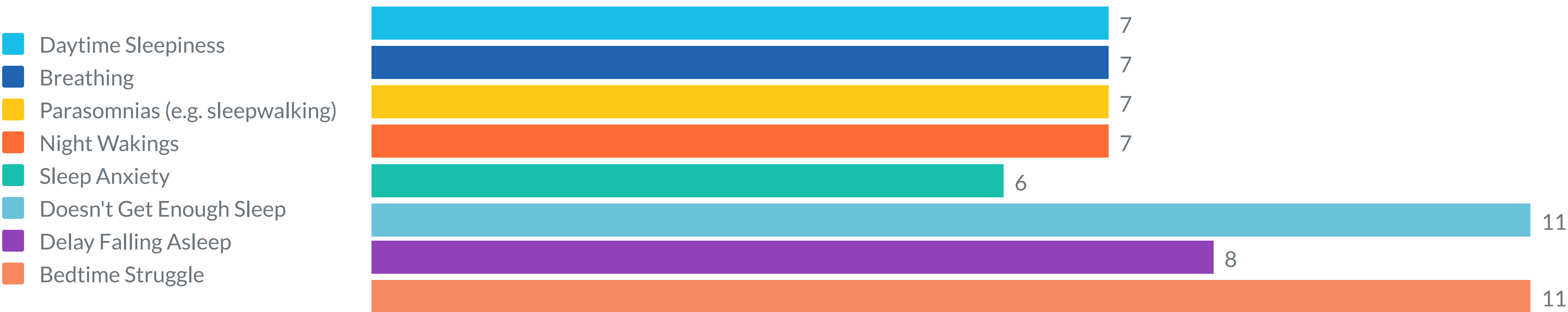
Overall Concern for Sleep Problems in children with a 16p11.2 distal deletion



“ It is important to study sleep in children with rare neurodevelopmental disorders because these children are at higher risk for sleep problems, which can negatively impact their behavior and daily functioning. ”

-Alison Holbrook, PhD

Areas of Sleep Concern in children with a 16p11.2 distal deletion*



• The bars in the graph show the number of children with a more significant problem in each aspect of sleep
• Top Sleep Problems show the most frequently reported problem behaviors related to sleep. Areas of Sleep Concerns are made up of several sleep problem behaviors that are similar in type. Top Sleep Problems may not result in increased concern for Areas of Sleep if similar behaviors are not also a problem.