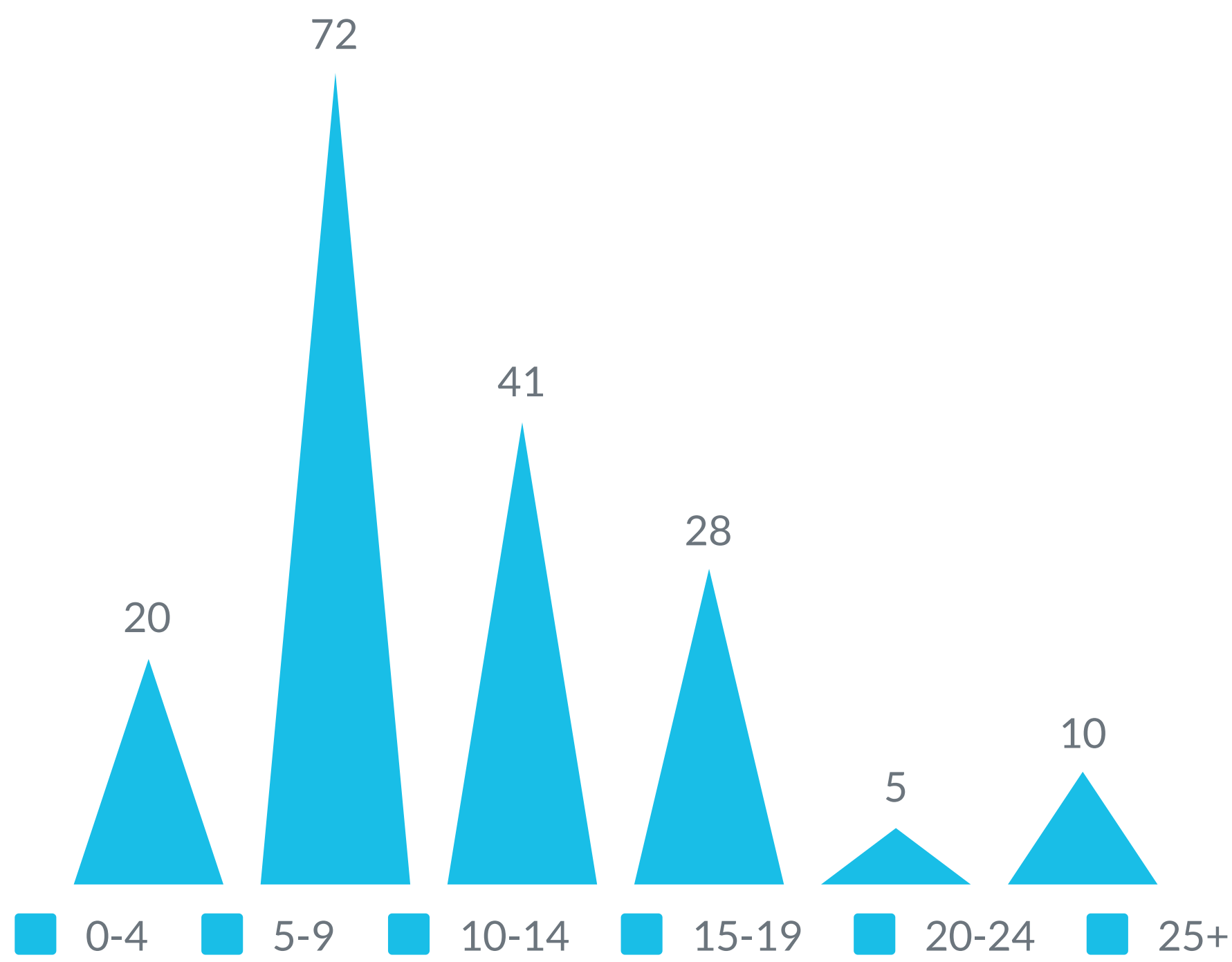


# Simons Searchlight Registry Update 16p11.2 Deletion

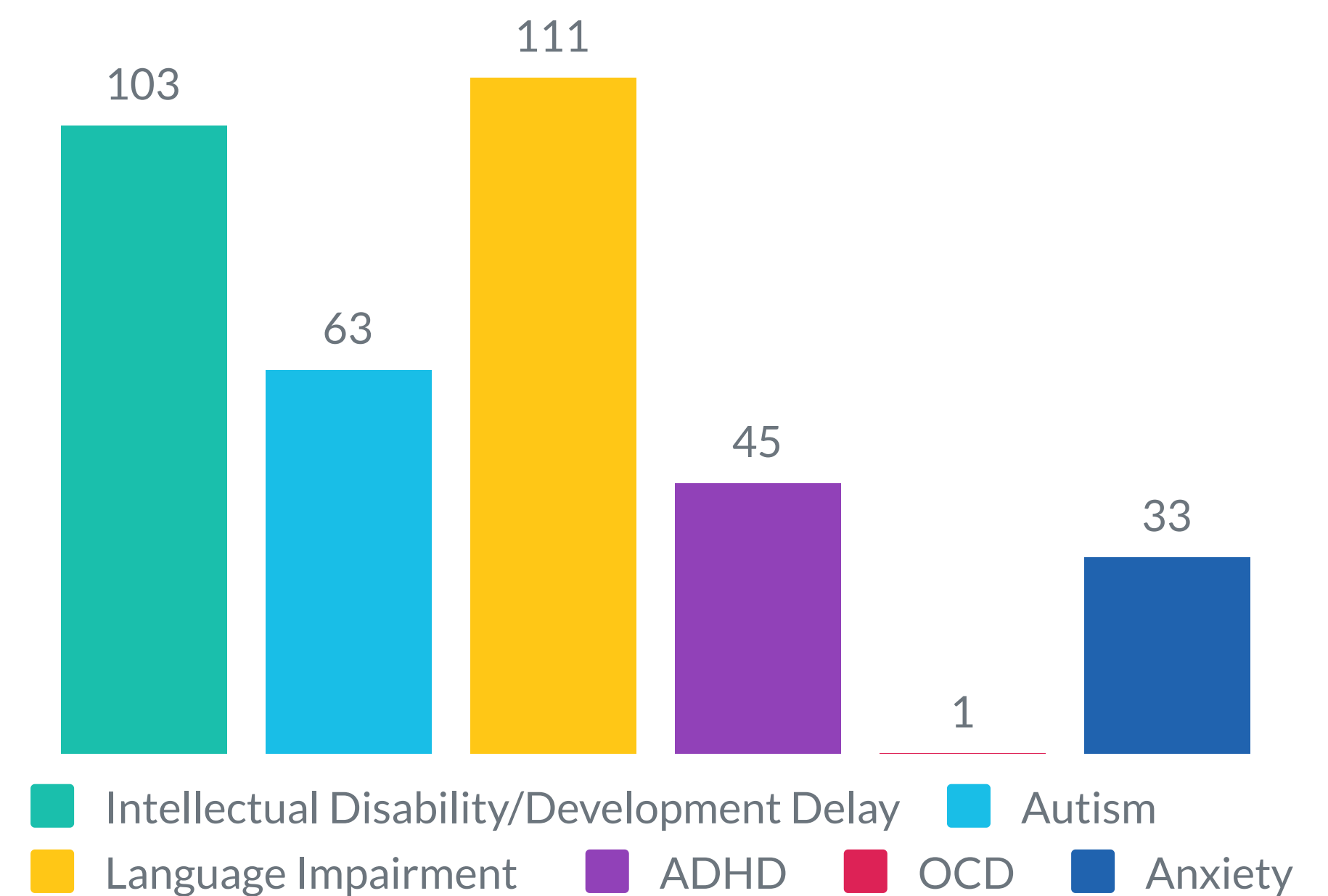
September 2021

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 176 participants with a 16p11.2 deletion.

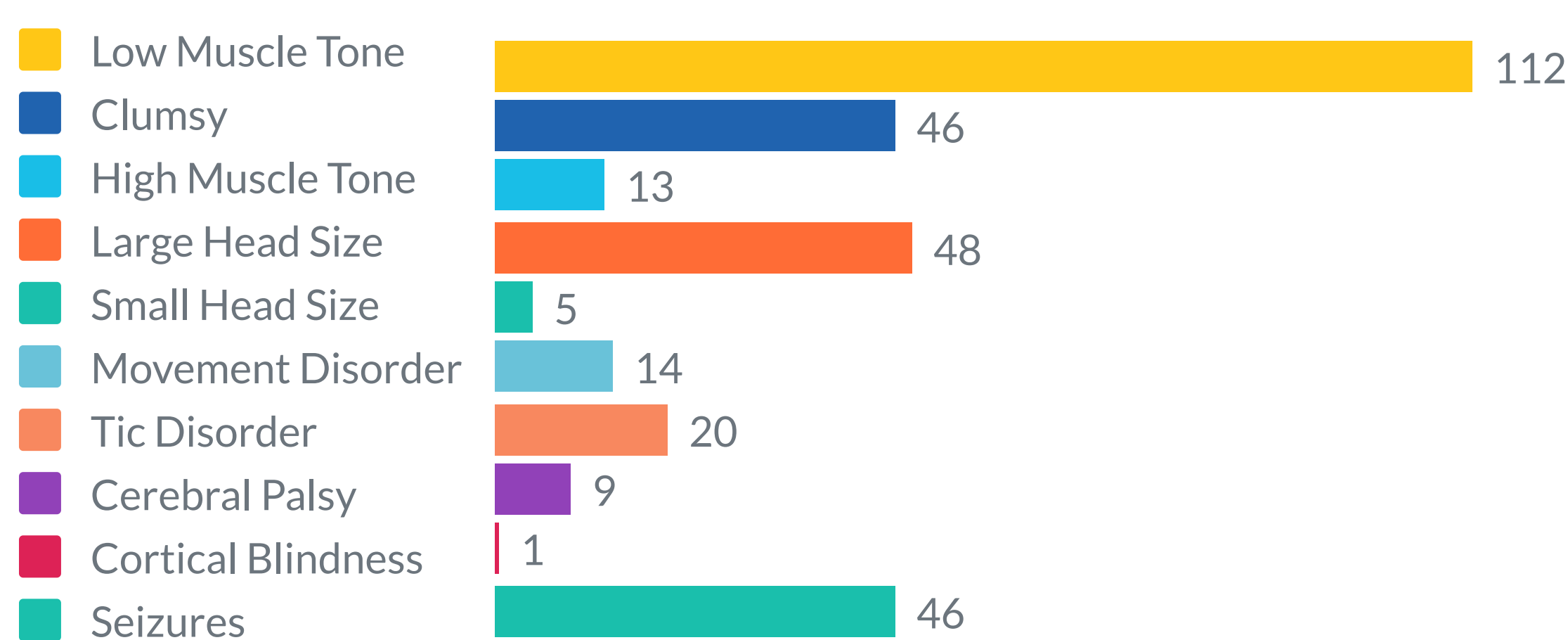
## Ages in Years



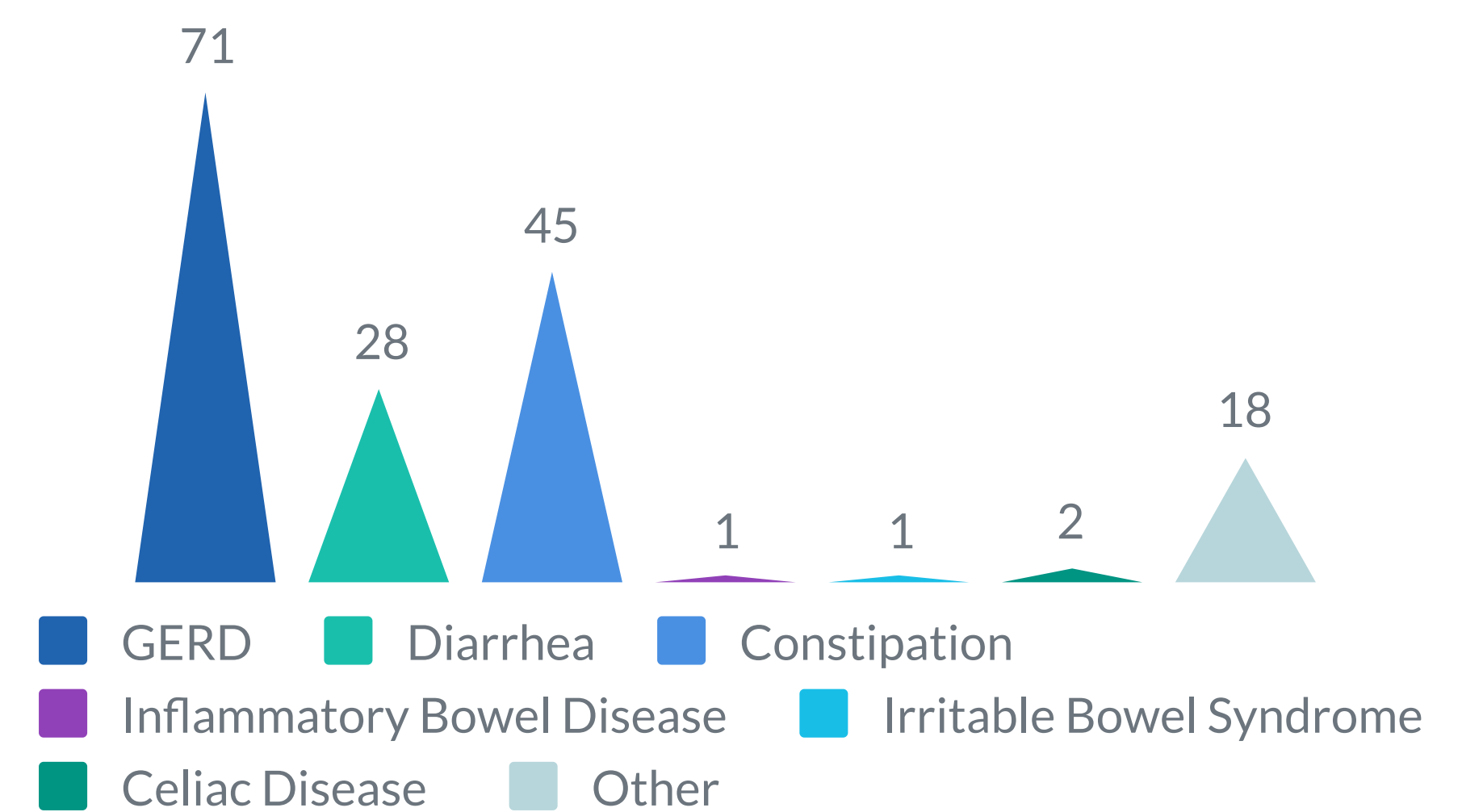
## Developmental & Behavioral Diagnoses



## 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/16p11-2-deletion/](https://simonssearchlight.org/research/16p11-2-deletion/).

## Participation & Registration

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

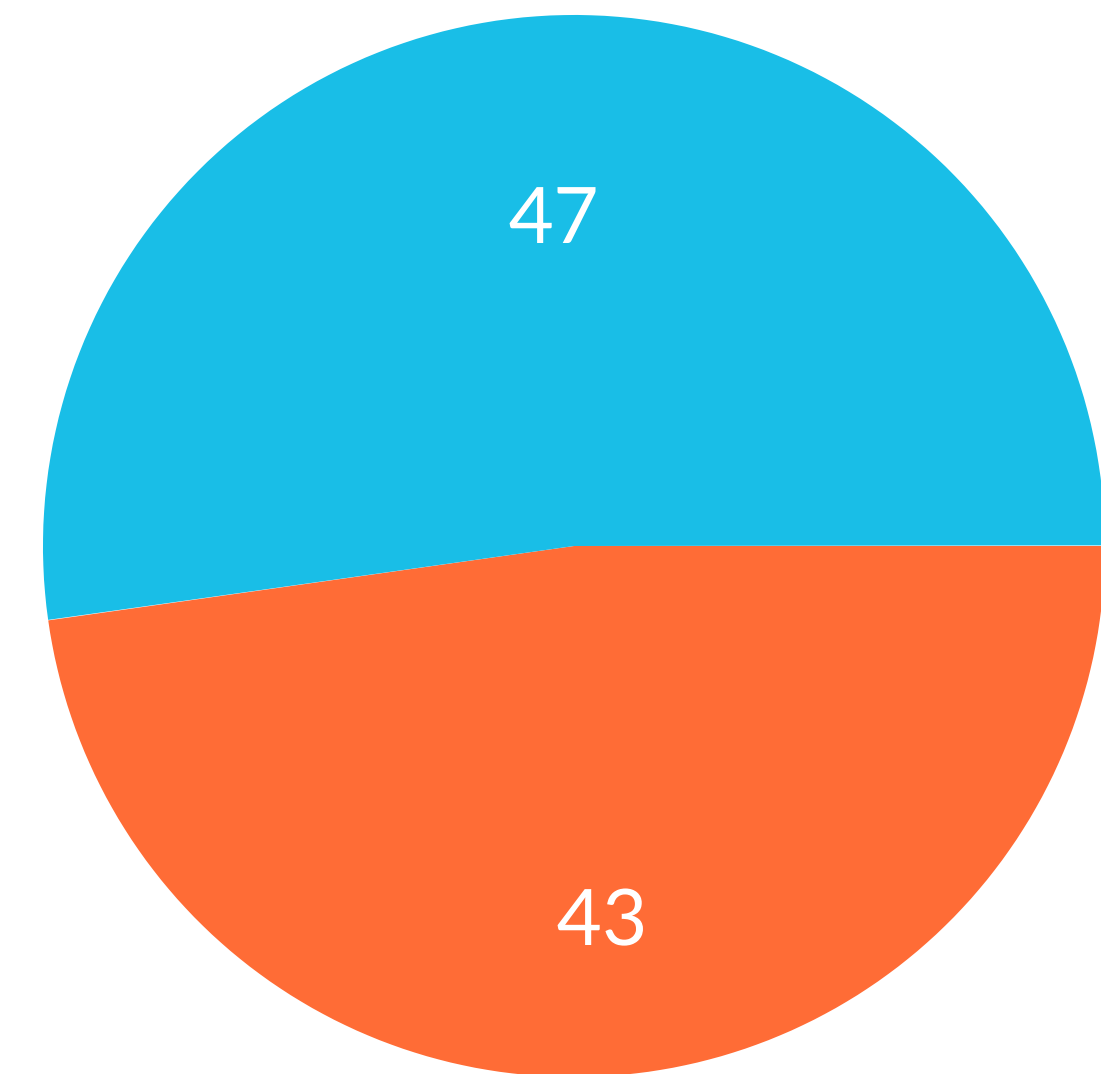


# Information Spotlight: Sleep Concerns

## Overall Concern for Sleep Problems in 16p11.2 Deletion Carriers

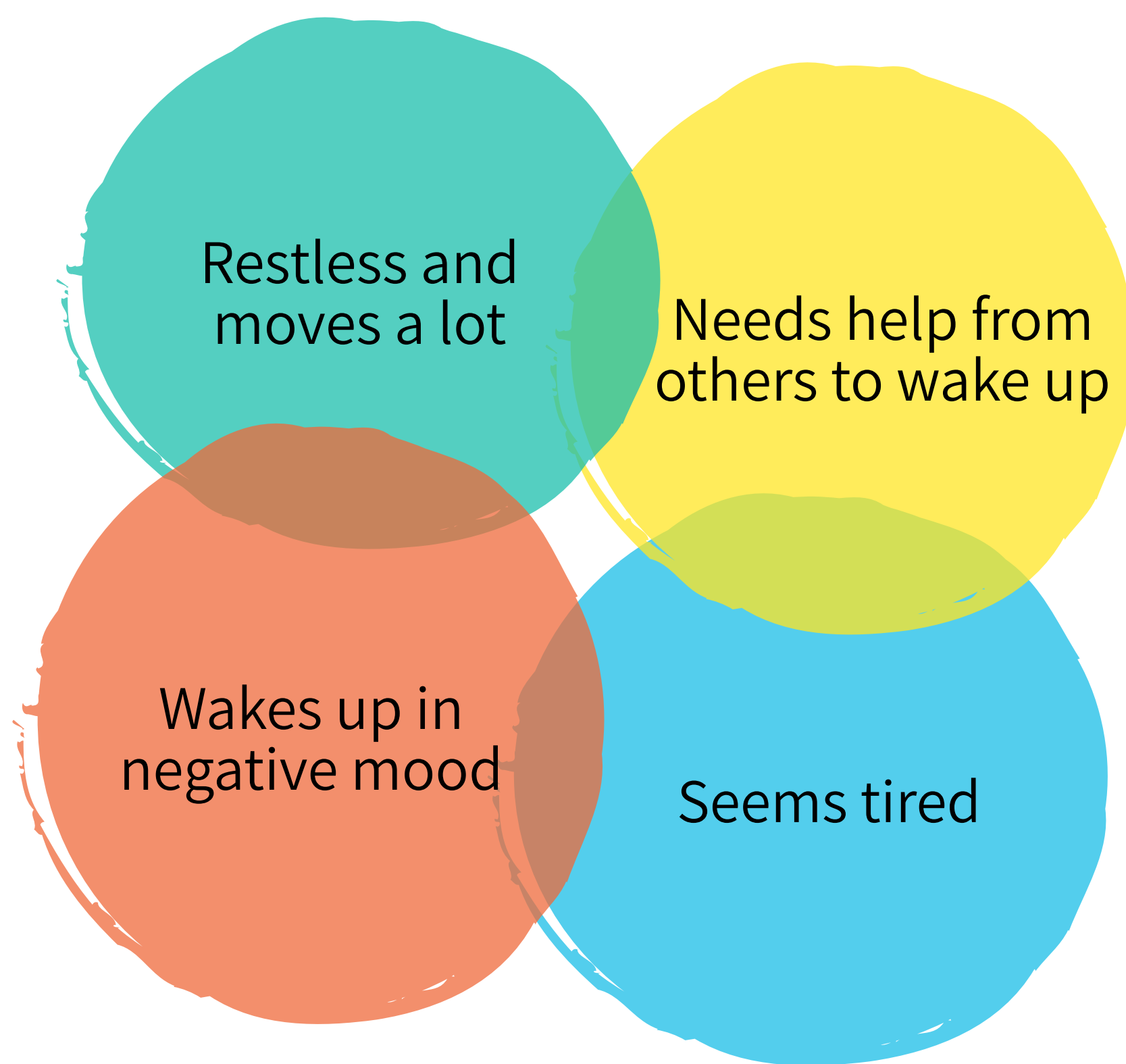
**The Children's Sleep Habits Questionnaire** is a survey used to understand sleep habits and possible sleep problems in children. All individuals were between 2 and 18 years of age.

90 children with a 16p11.2 deletion are represented.



High likelihood of sleep problems (47.78%)  
Low likelihood of sleep problems (52.22%)

## Top Sleep Problems for people with a 16p11.2 Deletion

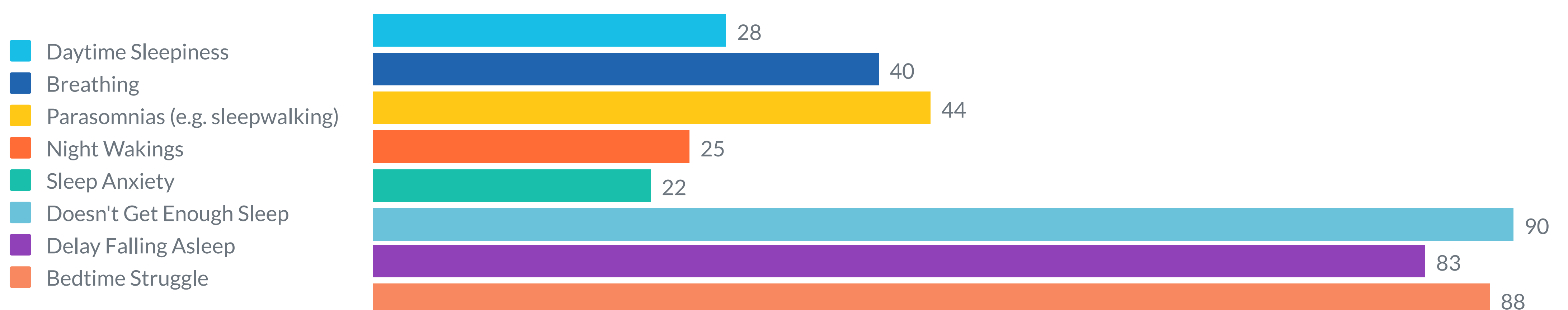


It is important to study sleep in children with rare neurodevelopmental disorders because these children are at higher risk for sleep problems, which can negatively impact their behavior and daily functioning.



-Alison Holbrook, PhD

## Areas of Sleep Concern in for people with a 16p11.2 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.