Children with intellectual disability (ID) are more likely to have mental health and behavioural difficulties than typically developing children.

More than half the children in IMAGINE-ID have a serious behavioural or mental health problem.

**Mental Health**

- Over a third have Autism
- One quarter have ADHD
- 1 in 7 is seriously Oppositional and Defiant
- 1 in 8 children has significant problems with their emotions

**Emotional Difficulties**

- One out of every 8 children has an anxiety disorder.
- Some have non-specific worries (1 in 12) some worry a lot about separation from their parents (1 in 40) and others are really scared of social situations or other more specific things such as animals or insects (1 in 60).

<table>
<thead>
<tr>
<th>Anxiety Disorder</th>
<th>In Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other anxiety disorder</td>
<td></td>
</tr>
<tr>
<td>Social phobia</td>
<td>1%</td>
</tr>
<tr>
<td>Specific phobia</td>
<td>2%</td>
</tr>
<tr>
<td>OCD</td>
<td>3%</td>
</tr>
<tr>
<td>Generalised anxiety disorder</td>
<td>7%</td>
</tr>
<tr>
<td>Separation anxiety disorder</td>
<td>8%</td>
</tr>
</tbody>
</table>

- Very few children were depressed (about 1 in 200).
Children with autism in IMAGINE ID

Mental Health

More than **1 in 3** children in IMAGINE-ID has an Autism Spectrum Disorder (ASD).

Associated mental health problems include ADHD, Oppositional & Defiant behaviours, Anxiety and Tics.

Nearly half those with ASD have an *additional* mental health disorder.

Emotional and behavioural problems are *twice as common* in children with autism compared to children without autism.

In families where a child has autism as well as intellectual disability, parents are much more likely to feel stressed, and to experience problems with their own mental health.

Physical health

Children with ASD (as well as ID), were especially likely to have problems with:

- Sleep
- Feeding and eating
- Gastrointestinal problems

Nearly half of them have difficulties getting off to sleep and they wake up too early.

About one third have elaborate food rituals, habits or preferences and 1 child in every 6 eats stuff that is not meant to be eaten.

A quarter have severe constipation and 1 in 5 has reflux.
Sleep
Sleep disturbances are very common, and these are the main difficulties reported to us by parents of children who have an Autism Spectrum Disorder (ASD).

- Over a third of children are getting too little sleep, and those sleep problems are more common in children whose ID is associated with an ASD.
- Half have difficulty falling asleep, two thirds are not settling in their own bed and 1 in 4 has frequent night terrors or nightmares.
- If there are sleep difficulties, there is also higher parental stress.

Eating difficulties
Four out of five children with an ASD had feeding/eating problems. That is over three times as often as we find in typically developing children of the same age.

- Half of caregivers said that eating difficulties affect their child’s wellbeing.
- Over half said that that eating difficulties were a burden on the family.

If the child has serious eating difficulties, there is also a high risk of poor child and caregiver wellbeing in general.
Epilepsy

Nearly one in three children have had seizures. A wide range of seizure types were reported. The most common included absence seizures, generalised seizures, and febrile (fever-related) seizures.

Distribution of seizure types within the IMAGINE ID cohort across children with a previous history of experiencing seizures.

Coping with children who have seizures is stressful. Parents/caregivers of children with seizures had poorer mental health and well-being than others.

Thank you so much for taking the time to complete our questionnaires! Your contribution is helping us better understand genetic conditions and will help families.

We hope to keep you updated with our IMAGINE ID findings through our newsletters, you can also visit the IMAGINE ID website to keep up to date with our news and events, visit us here>

http://imagine-id.org/