

CoIN Study Preliminary Findings



Our preliminary findings indicate striking impacts of the Covid-19 pandemic within families of children with rare neurogenetic syndromes.

The CoIN Study so far....



21%

of children have a diagnosis of autism spectrum disorder.



30%

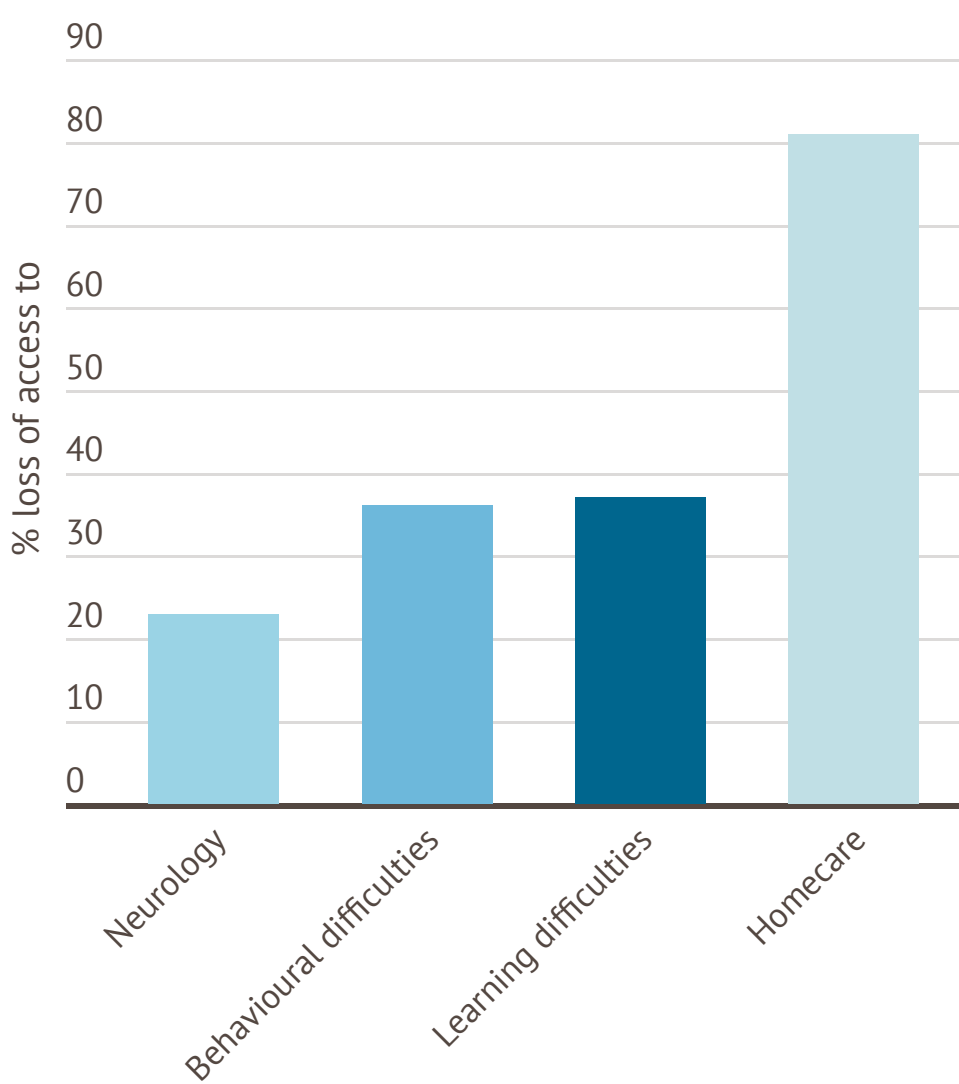
of children have a diagnosis of epilepsy.



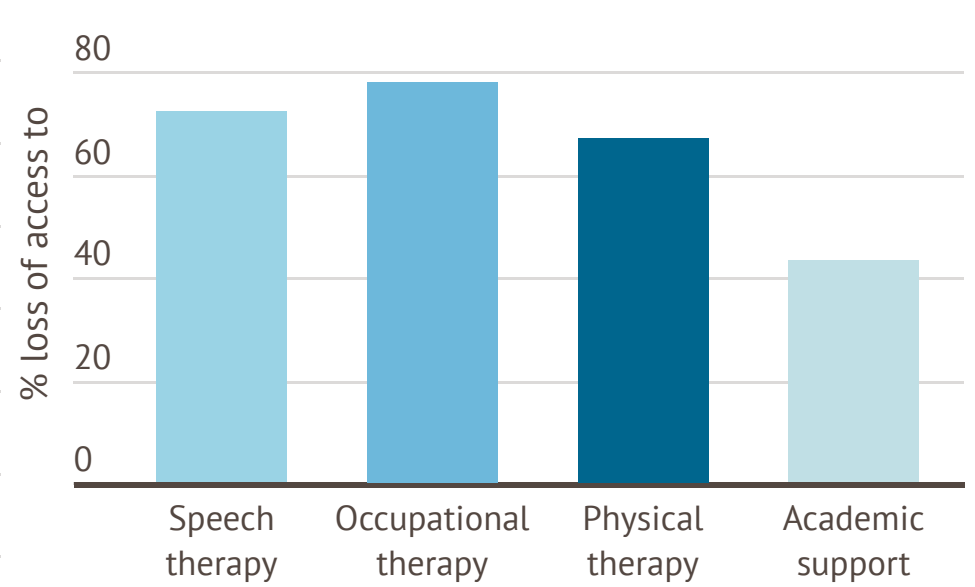
45%

of families have a child who is considered high risk or who has been shielding.

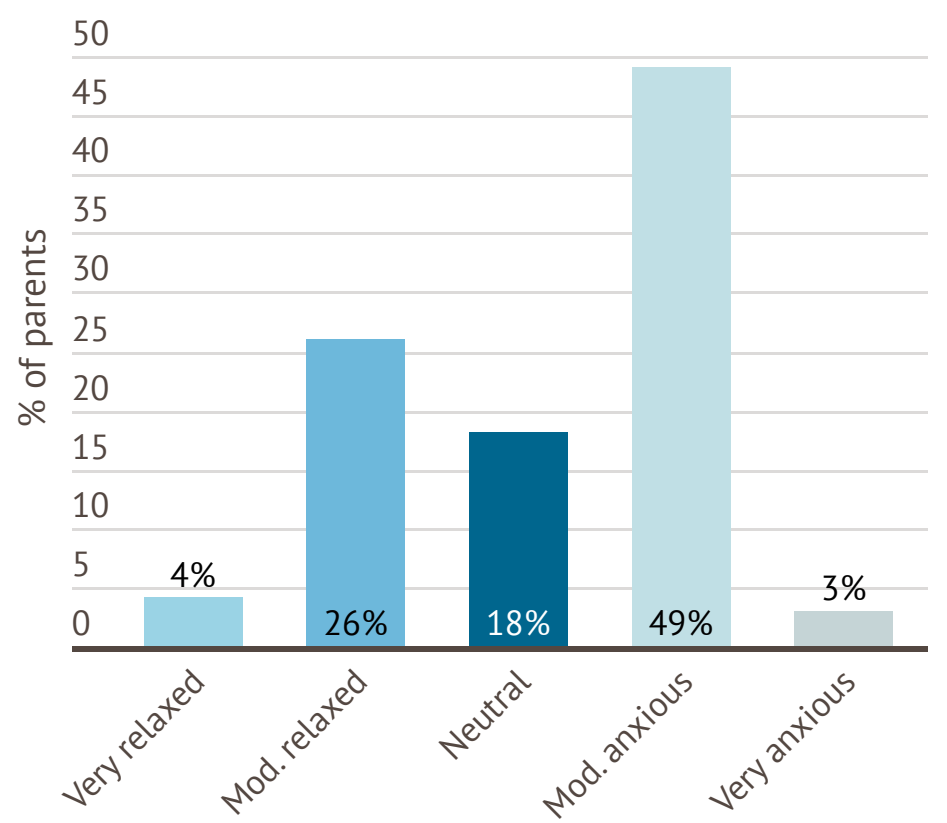
Loss of access to healthcare



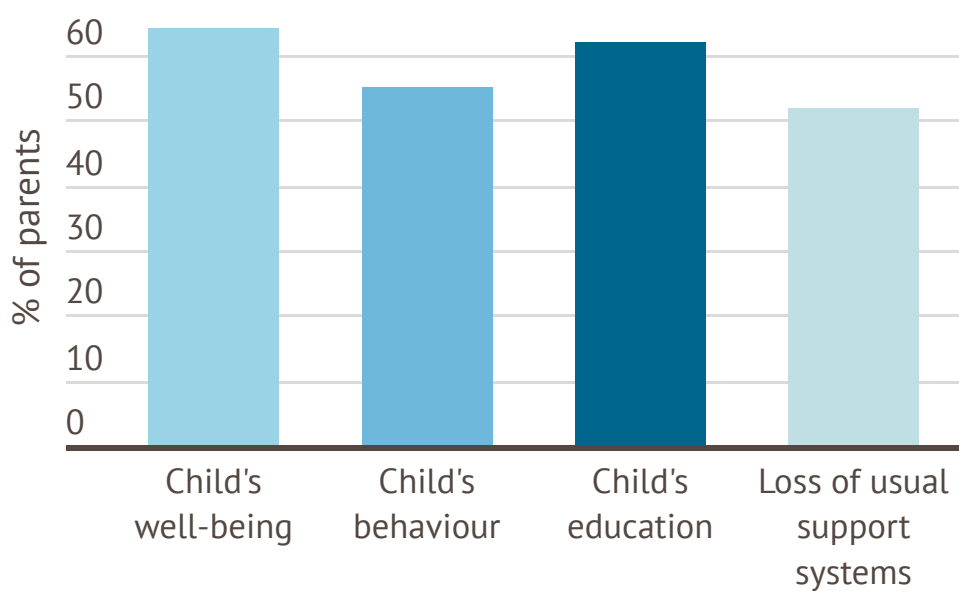
Loss of access to services



Parental anxiety



Top stressors

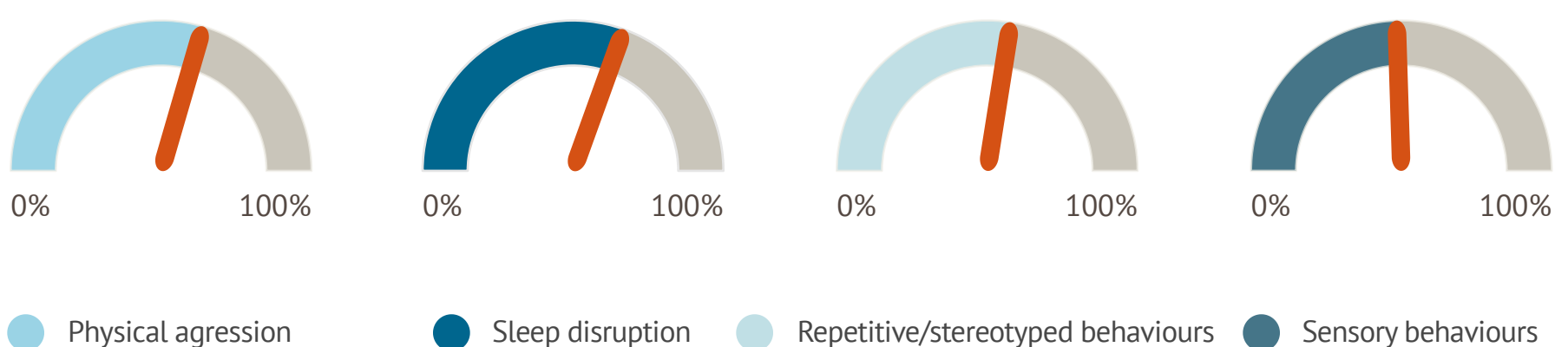


Over the past two weeks over half of parents reported that they felt either moderately or very anxious.

A high proportion of parents report feeling quite a lot or a great deal stressed about their child's well-being, behaviour, education and loss of usual support system.

Based on **170** parents

Child behaviour



Around half of parents report that their child's behaviour is more likely to have worsened recently. For example, 59% reported worsening in physical aggression, 61% reported worsening in sleep disruption, 55% reported worsening in repetitive/stereotyped behaviours and 49% reported worsening in sensory behaviours.