

CoIN Study Preliminary Findings - Children



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

The CoIN Study so far....

Based on **170** parents



21%

of children have a diagnosis of autism spectrum disorder.



30%

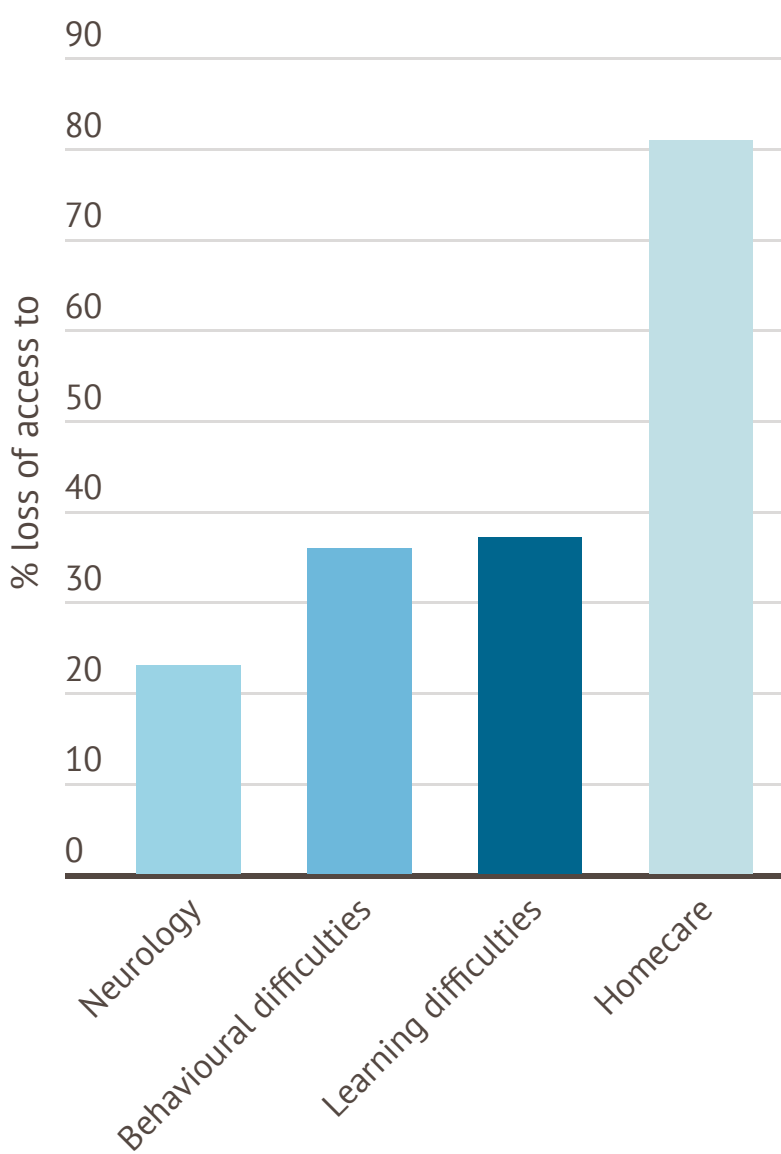
of children have a diagnosis of epilepsy.



76%

of children have moderate or severe learning disabilities.

Loss of access to healthcare

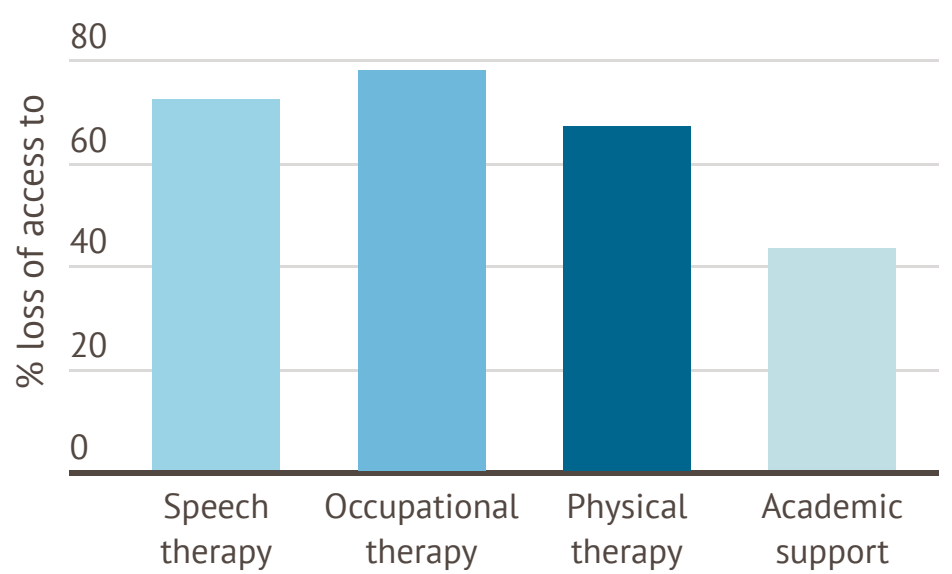


Of children that required access, 23% could not access neurology services, 37% could not access care for learning difficulties, 36% could not access care for behavioural difficulties. 81% lost access to in homecare, who previously received it.



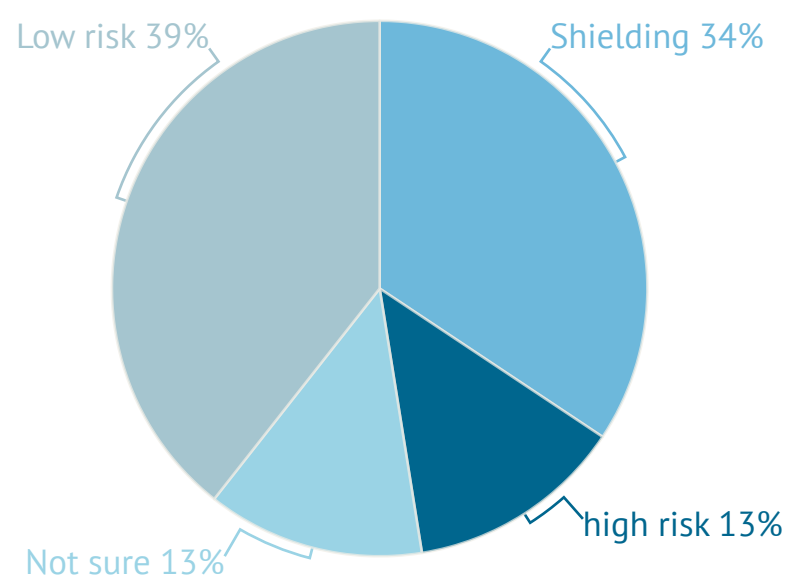
Over two-thirds of respondents noted that changes in access to healthcare have impacted upon their child's health or medical condition to some extent.

Loss of access to services



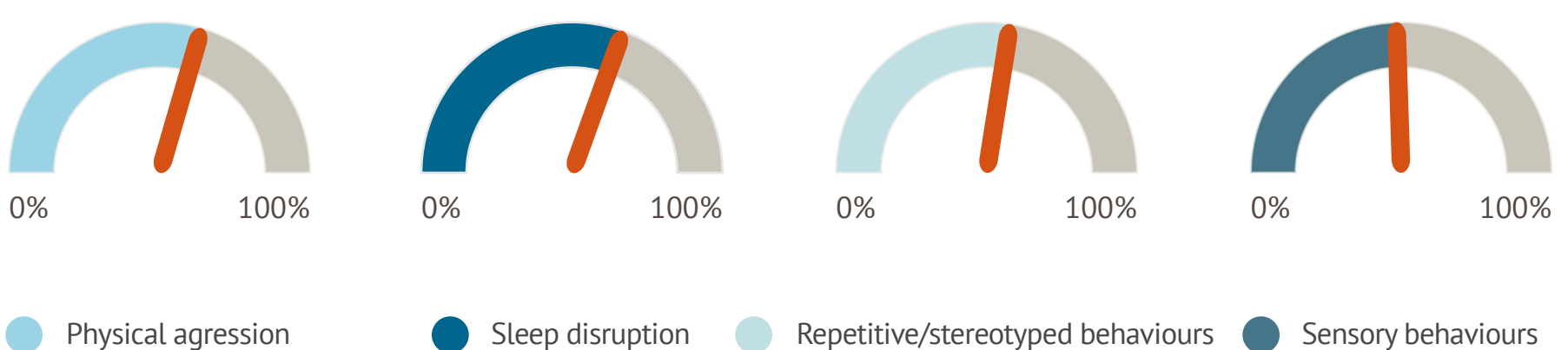
Of children that required access, 72% lost access to speech therapy, 78% lost access to occupational therapy, 67% lost access to physical therapy and 43% lost access to academic support.

Shielding



34% of children in our study have been shielding and 13% of children were considered to be at a higher risk than the general population.

Child behaviour



Over 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.