

The impact of COVID-19 on children born with cleft lip and palate

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The COVID-19 pandemic has impacted on the education and wellbeing of children across the world. While all children have been affected, it is important to understand specifically how those with additional health needs have been impacted. One such group is children born with a cleft lip and/or palate.

About the research

Around 1 in 700 children worldwide are born with either a cleft of the lip or a cleft of the palate or both.

Formed in early pregnancy, these gaps in the lip or the roof of the mouth are repaired surgically in the first year of life.

Nevertheless, children born with a cleft can experience low self-esteem and negative emotions.

They might also struggle at school and often have complex health needs.

This research looked at how children born with cleft lip and/or palate have been impacted by COVID-19.

A questionnaire was sent to parents in response to the first lockdown (July 2020) to ask about the impact of the pandemic on their children's surgeries and treatments, access to schooling and wellbeing.



Image credit: Cleft Collective

Policy implications

Children born with a cleft experienced significant and unique challenges during the first COVID-19 lockdown. They will likely require additional support to mitigate the long-term effects of the lockdown on their education, health and wellbeing.

Education

- Children born with a cleft require additional support from schools to catch up.
- Many children born with a cleft struggle at school compared to their peers. The lockdowns imposed as a result of the COVID-19 pandemic created additional challenges which are likely to exacerbate the education gap for this at-risk population.

Health and well-being

- The majority of planned surgeries (76%) were delayed due to the first COVID-19 lockdown, which could lead to greater demand on multidisciplinary cleft care services.
- Cleft specialist centres and local community provision may see greater demand to address problems related to function (for example, speech, breathing, feeding), well-being and appearance.
- Children may require additional support from psychology as a result of the negative emotions experienced during the pandemic.
- Access to the wider multidisciplinary teams for cleft were also affected by the lockdown and will likely also have impacts as a result of treatment being delayed.
- Online service provision needs to make sure that adequate electronic devices and technological support are available.

Key findings

We grouped our findings into categories of education, healthcare and emotions.

Education

“My child was uncomfortable to put their camera on during online lessons because of their cleft”

- The vast majority of home-schooled children (91%) did at least some work set by their teachers. However, only 12% of home-schooled children participated in live online lessons; the remaining 88% used online or paper learning resources.
- Of those children who were home schooled, 47% experienced no problems, but most experienced at least one difficulty, and many experienced more than one. These included difficulties adapting to remote learning, having limited quality or quantity of remote lessons, having no suitable place to learn, and not having a device or internet connection.
- Over 40% of children did not enjoy home-schooling, and these children were more likely to fall behind in their work.

While all children experienced difficulties with schooling during the lockdown period, children born with clefts are more likely to have low educational attainment and therefore are more at risk from the challenges experienced.

Emotions

“My child is very anxious. Being isolated for weeks, not going out and not seeing anyone has had a massive impact on them mentally, they have found some days really hard.”

- Most children experienced negative emotions, particularly being irritable or restless.
- Moods tended to improve slightly between early and later parts of the first lockdown as restrictions started to ease.

While many children experienced difficulties with their well-being during the lockdown period, the cumulative effect of these difficulties on top of the additional challenges faced by children born with cleft may lead to a bigger impact for this population.

Healthcare

“I am concerned that the delay to my child’s surgery may affect their speech”

- Nearly 4 out of 5 children had ongoing or planned treatment delayed as a result of the pandemic.
- Audiology or ear, nose, and throat (ENT) appointments were most frequently delayed, followed by speech and language therapy, dental, orthodontics, surgeries, and psychological therapy. Delayed appointments are more likely to lead to additional interventions being needed later in childhood.
- 1 in 2 children had their speech and language therapy delayed.
- For those who did continue to receive speech and language therapy, 74% was carried out online. Most parents thought these sessions were somewhat (61%) or very (31%) effective but a small number thought they were ineffective.
- Some parents identified specific challenges about the delivery of online speech and language therapy services which will need to be addressed in future planning of online service provision. These challenges included inadequate devices for online provision, technological problems during telemedicine sessions and child engagement during the sessions.

Responses	
Number of parental responses	1273
In relation to number of children	1041
Ages of children within sample	
All children	1-15 years
Number of school aged children	428
Number home-schooled during first lockdown	381 (89%)
Cleft type of children within sample	
Cleft lip only	256 (25%)
Cleft palate only	351 (34%)
Cleft lip and palate	415 (40%)
Other or unknown	21 (2%)

This research is part of The Cleft Collective, a UK-wide cohort study which studies the causes and consequences of being born with a cleft. The study collects participants’ genetic, environmental and psychological information, and links to medical and education records. Over 3000 families are taking part, making it one of the largest studies of its kind in the world.

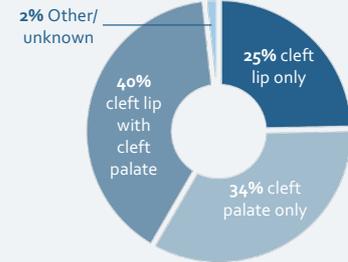
How were children born with a cleft affected by the COVID lockdown?

1273 parents or caregivers of **1041** children have sent back our questionnaire so far...

The children range from babies to 15 years old, but most were around age 4 - 5



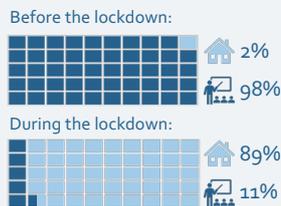
All the children in our questionnaire were born with some form of cleft lip and/or cleft palate



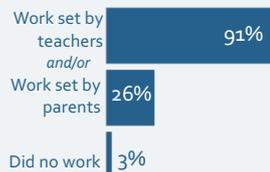
Education

428 children were school age. For lots of reasons, some children born with a cleft sometimes struggle at school and might find it particularly difficult to work remotely

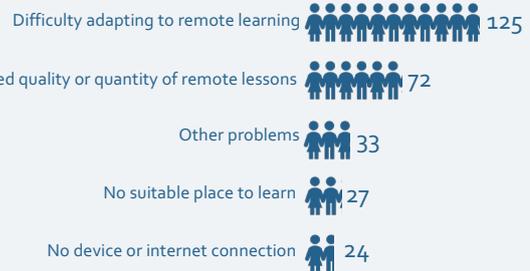
89% of children were homeschooled during the lockdown



Most homeschooled children did at least some work set by their teachers

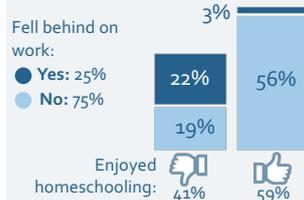


Of the 376 children who were homeschooled, 47% experienced no problems, but most homeschooled children experienced at least one difficulty



Only **12%** of homeschooled children participated in live online lessons, the remaining **88%** used online or paper learning resources

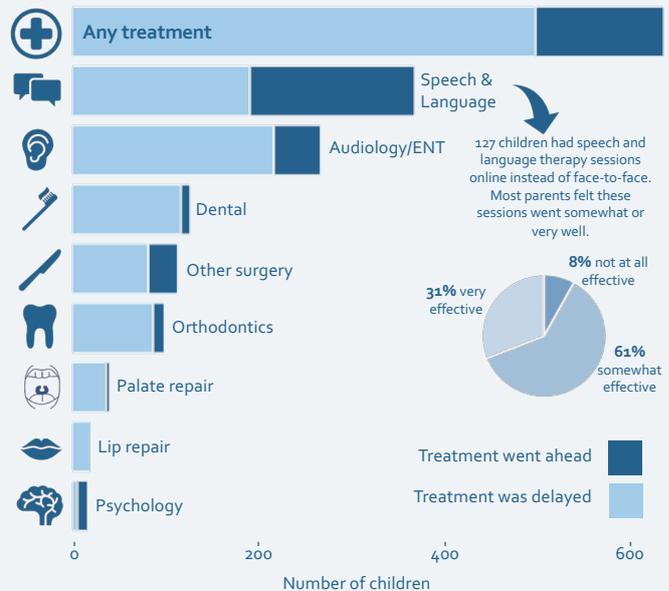
Over 40% of children did not enjoy homeschooling, and these children were more likely to fall behind on work



Healthcare

Children born with a cleft have complex health needs and undergo vital treatment from multiple disciplines

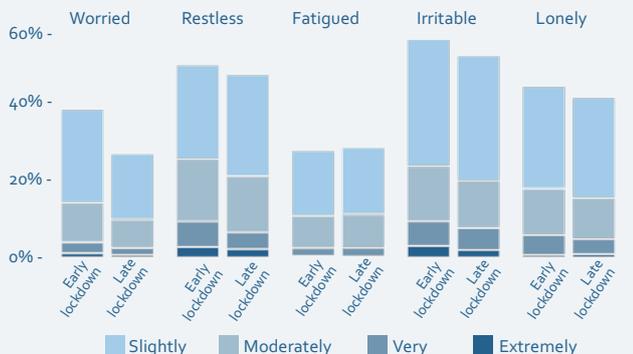
78% of all children with ongoing/planned treatments had their treatments delayed due to the COVID situation



Emotions

Children born with a cleft can sometimes suffer with low self-esteem and negative emotions

Most children experienced negative emotions to some degree, but moods tended to improve slightly between early lockdown and later when lockdown started to ease





Further information

Southby L, Harding S, Davies A, Lane H, Chandler H, Wren Y. Parent/Caregiver Views of the Effectiveness of Speech-Language Pathology for Children Born With Cleft Palate Delivered via Telemedicine During COVID-19. *Lang Speech Hear Serv Sch*. 2022 Jan 6:1-10. doi.org/10.1044/2021_LSHSS-21-00071

Southby L, Harding S, Davies A, Fell M, Wren Y. Speech-Language Pathology Provision During the COVID-19 Pandemic for Children Born With Cleft Palate in the United Kingdom - Parent/Caregiver Perspectives and Experiences. *Perspectives of the ASHA Special Interest Groups*. 2021 Dec 6:6 18-09-1819 doi.org/10.1044/2021_PERSP-21-00131

<http://www.bristol.ac.uk/cleft-collective/professionals/publications/>

Contact the researchers

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YouTube <https://www.youtube.com/channel/UCoPBxswpzThvtbv1UHNy8zQ>

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