Made to feel ‘more disabled’

Investigating the impact of Covid-19 on adults and families with cerebral palsy

The Bobath Centre investigated the impact of Covid-19 on adults and families of children with cerebral palsy during 2021.

Our findings highlight how the lack of services has impacted our community and brought about severe changes to their daily lives.

National Bobath Cerebral Palsy Centre
Charity number: 1191433
Regression in Physical Health
73% of adults had reduced ability to exercise and 59% experienced regression in their physical health. 42% of children's mobility regressed and 23% experienced delays in reaching their developmental milestones.

Mental Health
68% of adults reported experiencing depression on a typical day. 59% of adults reported the pandemic had a negative impact on their mental health.

Poverty & Unemployment
41% of adults were unemployed. 23% of adults either didn't have enough money to live on or were living month to month.

Lack of Access to Medical Equipment
41% of adults and 11% of children lacked access to appropriate medical equipment to support their needs.

Discrimination
100% of adults had faced discrimination. 70% felt ignored and patronised, 50% had been verbally attacked and shockingly, 18% had been attacked physically.

Almost all parents said their child had been treated differently. 75% had been ignored and 62% felt others had been uncomfortable around them.

“The service provision for my child prior to Covid was poor and now it feels as if it is being used as an excuse for poor service.”
Lack of Cerebral Palsy Health Checks

77% of adults hadn't been offered an annual review by health professionals. 62% of children hadn't been given timely medical reviews.

Gaps in Services

Adults reported improved access to annual medical reviews and mental health support is needed. Parents reported their children needed appropriate medical reviews and access to physiotherapy.

Lack of Access to Health Services

Almost all children and adults live in pain. Of those living in pain and discomfort, 91% use therapy for their pain relief.

Every age group reported therapy as more important for their pain relief than medication. Yet the majority of adults and children lacked access to relevant therapy.

59% of adults and 42% children lacked access to appropriate health services.

“They think someone in a wheelchair can’t talk and have a voice.”

“As a family, we feel more isolated than ever before.”
The needs of people with cerebral palsy are not being met appropriately

Our reports highlight gaps in services for both physical and mental health. For example, adults rated annual reviews as helpful for managing their cerebral palsy, but less than a quarter received them. The NICE* guidelines recommend an annual review as "an opportunity to identify changes; assess clinical and functional needs; check for problems and co-morbidities; and make sure that the person's needs are being met."

*National Institute for Health and Care Excellence

More Help Needed for Families

Many children's education has been impacted, as their Education, Health and Care Plans (EHCP) had been disrupted.

Parents told us their child's access to almost all health professionals had declined and services have yet to return to pre-lockdown levels.

Equality for All

There is a shocking prevalence of discrimination faced by individuals with cerebral palsy.

Many adults live in poverty and struggle to make ends meet.

Our full reports are available here or bit.ly/bobathsurvey2022

---

National Bobath CEREBRAL PALSY CENTRE
Regal Way, Tandy House, WD24 4YE
www.bobath.org.uk
T: 020 8444 3355
Charity number: 1191433

contact@bobath.org.uk
@bobathcentre
@Bobath_Centre
@bobathcentre
bit.ly/bobathcentre

Special thanks to our researchers Raquel Fantoni and Sophia Sheih for their invaluable work and the survey participants for their time.
Copyright © 2022 National Bobath Cerebral Palsy Centre. All rights reserved.