

New video by adults with cerebral palsy shows how physio barriers can be overcome

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A new animated video—released today on World Cerebral Palsy Day (October 6)—highlights how hard it is for adults with cerebral palsy to get the physiotherapy help they need, and recommends ways in which

future services could be shaped.

The video was scripted and voiced by adults with [cerebral palsy](#) (CP) in partnership with researchers they had spoken to about their [personal experiences](#) of how well [physiotherapy](#) and physiotherapy services meet their needs.

These interviews, and the production of the video, took place as part of studies led by Brunel University London, of which the findings offer insights to physiotherapists, [policy makers](#) and healthcare organizations who have the potential to shape future service development.

Cerebral palsy is a condition affecting about 1 in every 400 children in the UK, and can affect their movement, coordination and development, to varying degrees from mild to severe impairment. Improvements to life expectancy mean that there are now an estimated three times as many adults with CP as there are children with the condition.

These adults can have weakness, fatigue, [muscle stiffness](#), and pain in their muscles and joints, which may worsen or present as a new onset with age—and they are more likely than other adults to experience diabetes, stroke and chronic respiratory conditions.

"Despite this great need for physiotherapy services for adults with CP, access to services in the UK appears somewhat chaotic overall," said Gemma Cook, the doctoral researcher at Brunel who led one of the studies. "Children with CP get far more well-organized help. But little was known about how adults with CP access and experience physiotherapy services in the UK, so we designed a study to listen to and understand their perspectives, bringing their voices to the fore."

The researchers interviewed 22 adults with CP, and with a wide range of needs and experiences. The individual stories included a music festival

fan who needs regular physiotherapy to maintain her ability to transfer from her wheelchair to a toilet by herself, and also an adult who felt abandoned by services when they turned 18. "You still have the condition, but everybody's closed their book on you, basically... You're just pushed off a cliff," they said.

These interviews revealed that:

- Adults with CP found it difficult to identify and access specialized physiotherapy services, and to get information and advice to help them best manage their condition.
- Adults with CP need physiotherapy services throughout the different phases of their lives, to meet their present needs, and to anticipate and—where possible—prevent future needs.
- Participants placed a high value on person-centered physiotherapy, which involves individualized treatment and valuing patient empowerment and priorities.

"We heard how adults with CP try to access physiotherapy through several different ways," said Cook. "They can go to their GP to get a referral. In some services, they can self-refer. They can go to charity services, and they can also go to private services. But the particular needs of adults with CP are hugely varied, and there isn't a clear pathway to make sure an individual reaches the right service to meet their needs."

For the participants who did find the services they perceived as meeting their needs, they are highly valued. "And that can really help the quality of their lives," said Cook. "Not just from a physical perspective, but through their ability to keep and thrive at their jobs, and through their ability for social interaction."

The team also conducted an [online survey](#) of over 160 adults in the UK and Ireland, to gather perspectives of adults with CP on physiotherapy,

which found that around 4 in every 5 participants experienced pain for more than 3 months, with a similar amount reporting a decline in mobility since turning 18, and having at least one fall in the past year. Nearly 2 in every 3 participants sought out physiotherapy for problems related to walking or mobility decline, and a similar amount reported that they cannot access the physiotherapy services they need.

The adults with CP took the most meaningful findings from the studies and worked with the researchers to create the animation, including that physiotherapists should work in partnership with adults with CP to review existing provision and to develop new services—working together to design what those services should look like, who should staff them, how they are funded, and to identify links to other services.

The video—also available on YouTube to watch and share—urges that services should be clearly signposted, accessible and flexible, as well as offering support throughout people's lives.

Brunel physiotherapy expert Prof Cherry Kilbride, who worked on the studies with Cook and colleagues including Dr. Betty Cassidy in the UK and Manjula Manikandan in Ireland, added that they recommend that the person-centered approach is adopted as the 'foundational philosophy' guiding physiotherapy services and interventions for adults with CP.

"More specialist physiotherapy services are urgently needed to meet the needs of adults with CP in the UK," said Prof Kilbride. "By listening to their needs and by working in partnership with them, we can shape services that improve care and support throughout adulthood. I recommend that people share this animated video to raise awareness of the difficulties experienced by [adults](#) by CP, and to advocate for their needs."

In addition to the video, two different studies were published in

Disability and Rehabilitation.

More information: Gemma Cook et al, Understanding physiotherapy and physiotherapy services: exploring the perspectives of adults living with cerebral palsy, *Disability and Rehabilitation* (2022). [DOI: 10.1080/09638288.2022.2062060](https://doi.org/10.1080/09638288.2022.2062060)

Manjula Manikandan et al, Access, use and satisfaction with physiotherapy services among adults with cerebral palsy living in the United Kingdom and Ireland, *Disability and Rehabilitation* (2022). [DOI: 10.1080/09638288.2022.2087760](https://doi.org/10.1080/09638288.2022.2087760)

Provided by Brunel University

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