

**These observations are my personal perspectives from the combined position of being a qualitative academic researching the lived experiences of adults with Cerebral Palsy; a policy expert in international disability human rights; and a neurological physiotherapist who has worked in specialist clinics for adults with CP.**

### **Reflections on Transition**

*Timing:* Transition does not necessarily occur at the age of 18. Adults with CP often seek services such as physiotherapy later, for example in their late 20s. This is usually triggered by experiencing new onset bodily changes such as pain, stiffness, and changes in mobility status. Reflecting the differences across individuals, the transition period should therefore be considered as occurring over a number of years rather than at a single point in time.

*Lack of Services:* On seeking services, and in contrast to the continuous services experienced during childhood, adults with CP find it difficult to find appropriate services to meet their needs. In addition to the lack of services and unmet need, adults with CP have also reported feeling shocked and abandoned by those who they expected would be able to offer support throughout their lives.

*Fragmented Services:* As well as a lack of services, people also commonly find fragmented services that are not designed specific to their needs. This can leave people feeling insecure and confused. Even if services are eventually found, an overwhelming sense of uncertainty can prevail because there is no way of knowing that they have found the services most appropriate to them or that these services will be sustained throughout their lives.

*Complex Lives:* Adults with CP lead complex lives and are often dependent on multiple services simultaneously. Seeking out these multiple different services is a complex and relentless exercise, and can leave people feeling fatigued, fighting a constant battle, sometimes completely alone. Adults with CP have a higher incidence of anxiety and depression than adults without CP. However, satisfactory service delivery can have a deep and positive impact on wellbeing.

*Lifelong Impact on Personhood:* Experiences of transition are not one-off and can have a profound impact on personhood. Where people have negative experiences, they can feel dehumanised, which can lead to a sense of mistrust. This can affect a person throughout their lives, not only impacting on their present and how they engage with services in the here and now, but also how they look to their future.

*Misunderstood Condition:* The heterogenous presentation of CP leaves it vulnerable to assumption and misunderstanding by all members / sectors of society. For example, CP has historically been considered a non-progressive condition, but adults with CP experience changes in their physical capacity in adult life. Nevertheless, the legacy of the 'non-progressive' assumption is that services for CP remain frontloaded to children, with many services ending at the traditionally acknowledged transition age of 18.

*A Condition in its Own Right:* CP is commonly compared to other conditions when looking to ideas for policy-improvement. However, this comes with risks, because the heterogenous needs of people with CP are unique, not only to the condition but also to the individual. For example, CP does not fit into common healthcare categories such as the separation of musculoskeletal and neurological services. More commonly persons with CP present with a combination of both musculoskeletal and neurological impairment, with the underlying main cause of new problems often indistinguishable.

## Recommendations

- Service re-design, in particular around transition, needs to take an intersectoral approach (across healthcare, education, vocational training & employment, and socialisation & other leisure activities) putting streamlining of services as a top priority. To work towards this, all stakeholders involved in improving policy around transition should avoid working in siloes.
- Services for people with Cerebral Palsy need to be lifelong, and take a life-cycle approach, and not be designed around fixed transitional time points.
- Some suggest that having a central hub for signposting to services would make a good model. A central hub could include an email service, where people with CP can have open access to remote professional guidance with problem solving, supporting them in navigating often complex lives.
- Evidence suggests that where good physiotherapy services are found they are highly valued, in particular those that take a person-centred partnership approach. Some suggest that physiotherapy could play a central role in such service hubs.
- Persons with CP, in particular young people with CP need to be at the centre of all service design. They should be involved in every step of the decision-making process, from the very beginning to the very end.
- Service improvement for CP should be specific to the needs of people with CP, and not compared to other conditions, or modelled to services that have been set up for other conditions.
- Services should be designed with in-built flexibility to accommodate the needs of the individual and their needs change through time.

These are the observations of Gemma Cook, Doctoral Researcher, Brunel University London, [Gemma.cook2@brunel.ac.uk](mailto:Gemma.cook2@brunel.ac.uk), shaped by the below sources:

Two recently published research articles on physiotherapy experiences of adults with CP, which as well as research activities, involved regular consultations with advisory groups:

- <https://www.tandfonline.com/doi/full/10.1080/09638288.2022.2062060?src=recsys>
- <https://www.tandfonline.com/doi/full/10.1080/09638288.2022.2087760>

A co-produced animation based on the results of the above studies, to be published imminently in the Autumn of 2022.

A mixed-methods systematic review on adult CP services:  
<https://onlinelibrary.wiley.com/doi/10.1111/dmcn.15097>

Currently completing a PhD that uses art to understand the policy-experiences of adults with CP, hosted by Brunel University London, under the Grand Union Doctoral Training Pathway and funded by the ESRC