



Response to Consultation Questions – Disability Action Plan

Cerebral Palsy Scotland

Cerebral Palsy Scotland is the only organisation dedicated to helping people with cerebral palsy of any age throughout Scotland. Our mission is to help people with cerebral palsy (CP) build skills, knowledge, confidence and relationships. We advocate for the CP community to have life-long access to knowledgeable, compassionate services and support.

The charity, previously known as Bobath Scotland, was founded in 1995 by families in Scotland who had grown frustrated at travelling to London to get specialist therapy for their children who were living with cerebral palsy. In 2012 we expanded our provision with the launch of our therapy service for adults with cerebral palsy. The charity is a Scottish Charitable Incorporated Organisation, registered with the Office of the Scottish Charity Regulator (OSCR).

Our services have continued to grow and develop, guided by what's best for the CP community. These have included the launch of our annual Cerebral Palsy Scotland conference and exhibition in 2013, the provision of group therapy for babies, after school primary school children and teenagers (funding permitting), including mental health and wellbeing within our therapy offer and the development of a CP Support service

We treat anyone of any age with cerebral palsy from across Scotland, we support families and carers to better understand the needs of people with CP and we work collaboratively with professionals who support people with CP within statutory services through partnership working and training. In the policy sphere, we advocate for the CP community to have life-long access to knowledgeable, compassionate services and support.

Cerebral Palsy

Cerebral Palsy (CP) is the most common cause of physical disability in childhoodⁱ. It is an umbrella condition that affects everyone differently and to a greater or lesser extent. It will always affect movement and physical development. As well as affecting movement, CP can affect other areas of function:

- 1 in 3 are unable to walk
- 1 in 4 are unable to talk and will use alternative methods of communication
- 3 in 4 experience pain
- 1 in 4 has epilepsy
- 1 in 2 has a learning disability
- 1 in 4 has bladder control issues
- 1 in 5 has a sleep disorder
- 1 in 5 has saliva control problems

There is no cure for cerebral palsy and although the damage to the brain does not worsen, the effects of the condition become more debilitating with age. As a person with CP grows, they can develop secondary muscular skeletal problems, such as increased tightness in muscles and joints and

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dislocations. This can change a person's physical abilities over time. People can also experience increased issues with pain and fatigue.

Children with CP in Scotland are seen through specialist children's services in their local communities and some will have regular reviews with consultant paediatricians. There are no specialist statutory services for adults with CP in Scotland, a situation recognised throughout the UK. Many people with CP are able to lead long and fulfilled lives, however, others require access to a range of services. Many adults have social care needs and rely on carers and PAs (personal assistants) in order to live their lives. Most adults access this support through general adult disability services. There is limited or no access to specialist input. Staying well, with regular access to specialist multidisciplinary therapy, is key to maintaining good health for people with cerebral palsy.

Elected Office

Cerebral Palsy Scotland welcomes any initiatives that support disabled people to be supported to seek elected office.

Accessible Playgrounds

Children learn and develop through play. Local playgrounds are also important for social skills and ensuring families have a safe place to go to play.

Looking after a child with CP is challenging. Too often families cannot identify places where they can go with their family as playgrounds that may be suitable for siblings are not suitable for their child with CP. This leads to further isolation for families and children with CP. Accessible playgrounds play a vital role in tackling this issue and supporting disabled parents as well as their children.

Cerebral Palsy Scotland welcomes the proposal to create guidance for playground accessibility and would argue that accessibility standards should be mandatory. It should be noted that accessibility does not mean playgrounds are not accessible, or fun, for all children, but rather they are inclusive by design and build from the start.

We note that Inspiring Scotland has produced a guide for creating accessible playgrounds: [Free-to-Play-Guide-to-Accessible-and-Inclusive-Play-Spaces-Casey-Harbottle-2018.pdf](https://inspiringscotland.org.uk/wp-content/uploads/2018/07/Free-to-Play-Guide-to-Accessible-and-Inclusive-Play-Spaces-Casey-Harbottle-2018.pdf) (inspiringscotland.org.uk).

Finally, we stress that accessibility is far more than simply ensuring children can physically access a space, consideration should be given to how a child is made to FEEL included.

Emergency planning and Resilience work

Cerebral Palsy Scotland strongly supports increased disability inclusion in emergency planning and in resilience work. It was notable that the government's response to the COVID-19 pandemic did not consult with disabled people regarding how services were adaptedⁱⁱ. Cerebral palsy (CP) as a long term neurological condition was cited by Scottish and UK governments as being a condition that left you more at risk from Covid-19 from March 2020 onwards. As the country went into lockdown our

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organisation experienced a significant increase in enquiries and throughout the period of restrictions and beyond, rising levels of anxiety amongst people with CP and their families. For many people with cerebral palsy, as community services shut down, were severely restricted, or failed to catch-up post Covid-19, we were the only organisation that they could turn to for condition-specific advice.

Community physiotherapy, occupational therapy and other AHP services were not deemed to be 'essential'. With the closure of schools, many families did not feel confident to send their child into school, even if a place was available. Some adults with CP moved back to live with (sometimes elderly) parents and family for lockdown and some did not want to allow carers to enter their homes. During this time, there didn't seem to be any joined up approach with government to ensure that different departments took account of the unintended consequences of government actions, guidance and advice. People with cerebral palsy were not adequately considered and they felt abandoned and their needs ignored.

The closure of schools had an extremely detrimental effect not only on children with CP, but also their families. School time for children with CP is often more than just providing education. It is where therapy appointments happen, it benefits mental health and wellbeing and it provides vital respite for family carers. Many children with CP have 1-2-1 support for their learning in school. The restrictions put more pressure on families with children with CP were struggling to cope with the demands of physical care needs in addition to educational needs, the requirements of non-disabled siblings and potentially trying to work from home as well. For some this stress had specific physical health consequences. Many others reported feeling exhausted and unsupported.

Because it is not possible for services to identify people with CP, this led to issues identifying those who were being asked to shield during Covid pandemic. Despite Scottish Government's officials who were responsible for shielding reaching out to organisations like Cerebral Palsy Scotland, there was no coherent approach. Because people with CP could not be identified centrally, many approached their local GPs, paediatrician, allied health professionals or social workers to ask to be shielded. Many more chose to voluntarily class themselves as "shielding" compared to the actual numbers who received an official letter. People with CP fell through the gaps.

The lack of a cerebral palsy register meant that health and care and educational professionals did not have adequate data to identify people with CP within their communities. This led to difficulties in reaching vulnerable people and providing them with adequate support. Medication was seen as a priority, but physical therapy, occupational therapy or speech and language services were not, yet for people with CP, these are as vital to access on a regular basis as medication is for other conditions. Reviews were cancelled or postponed which resulted in children growing out of vital equipment (such as wheelchairs or sleep systems) or people not having their communications devices serviced or batteries changed, which meant they lost their ability to communicate.

Disabled people's organisations are essential to ensuring this work is successful. This needs to include organisations, such as SCOPE that support people with physical disabilities, umbrella organisations, such as the Neurological Alliance, and condition specific organisations, such as

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Cerebral Palsy Scotland, should be able to contribute as well. Co-ordination with devolved administrations is also to be strongly encouraged, particularly regarding how individuals are identified and how public messaging is managed.

Disability Enabled Badge

Cerebral Palsy Scotland support any work to encourage wider awareness within businesses and services and their staff regarding issues for disabled people. The Disability Confident scheme for employers has been helpful since its creation, but it does not go far enough. Acquiring accreditation is only a first step, it's important to ensure this, and the proposed Disability Enabled Badge scheme do not become "tick box" exercises.

Latest data suggests that 24% of the UK population identify as disabled.ⁱⁱⁱ Therefore with no matter what sector businesses and services operate in, they are likely to interact with people with a wide variety of seen and unseen disabilities. Whilst the consultation document highlights the barriers the variability of different disabilities can lead to, we do not believe that just putting all training options together "under one umbrella" is realistic or achievable. Whilst there are large organisations that cover a range of issues, such as Scope, Mencap or Enable, for example, no organisation can truly speak for all disabled people.

Condition-specific awareness and training will add value and ensure perspectives remain open. Cerebral palsy is the most common cause of physical disability in children and whilst the majority of people with CP go on to lead normal life spans, there is very little understanding of the condition and its effect on people as they age.^{iv} Given the prevalence of a condition such as CP, Cerebral Palsy Scotland argue that if businesses, services and employers can get things right for people with cerebral palsy, they will also get things right for people with many other, less common conditions.

If the Disability Enabled Badge scheme had continuous learning and improvement built in, then there is value in enabling a "safe space" for people with disabilities to discuss their needs and feel confident to ask for assistance when required.

Special Olympics

Cerebral Palsy Scotland note that opportunities for people with CP to participate in track events are limited. We support the inclusion of Frame Running^v in any multi-sport event.

Raising the Profile of Assistive Technology

1 in 4 people with cerebral palsy are unable to talk and use alternative methods of communication. Too often children are not assessed as requiring support of Augmentative and Alternative Communication (AAC) until after they have started in education, and in many cases children and adults are not offered the appropriate device and ongoing support to use their device.

In Scotland, communication equipment and support legislation (part of the Health (Tobacco, Nicotine etc. and Care)(Scotland) Act 2016) places a duty on health boards to provide or secure the

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provision of communication equipment, and the support in using that equipment, to any person (children and adults) who has lost their voice or has difficulty speaking. However, our experience at Cerebral Palsy Scotland suggests that whilst communication devices may be provided, children's communication needs are not being assessed at an early enough stage and ongoing support through speech and language services is hampered by the workforce shortage and availability of speech and language therapists. Services, such as Call Scotland deal only with children, not adults, and their funding from Scottish Government has not increased since 2011, so services are stretched.

Cerebral Palsy Scotland welcome the government's plan to raise the profile of assistive technology. Our experience has shown that, in addition to communication, technology can be a game changer for people with cerebral palsy in the home (e.g. the use of smart speakers) or in education or at work (e.g. predictive text programmes and eye-gaze). However, we have also seen machines taken away from people once they leave education, people admitted to hospital without their communication device and social workers or other service providers not enabling time and space for service users with communication devices to be able to input to meeting discussions about their lives. We believe everyone has a right to be supported to communicate to the best of their abilities.

Wellbeing and Opportunities of Disabled Children

Cerebral Palsy Scotland welcomes a focus on cross-government opportunities.

As mentioned previously, cerebral palsy is the most common cause of childhood physical disability. Around 1 in 400 births will result in a diagnosis of CP. We fear that the needs of this population are being lost with the focus on children with social and behavioral impairments.

SEND

We have already engaged with the Department of Education on the SEND Improvement Plan where we have concerns around the lack of provision for children with a physical disability. We welcome the plan's principles of early identification of needs, targeted support to address individual needs and timely access to specialist services and support including specialist placements when appropriate. Whilst we appreciate the plan is setting out a broad strategy, we are disappointed there is no mention of physical disability or cerebral palsy throughout, despite reference to learning disability, early language, autism, behavioural challenges and sensory impairment. This has implications in the details of implementation, for example with additional training resources directed to these needs, but not, apparently, to physical disabilities.

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Transitions

Cerebral Palsy is regarded by service providers as a paediatric issue. Once a person with CP reaches adulthood there are no specialist services (as for example there are with other neurological conditions such as epilepsy, multiple sclerosis or Parkinson's). Access to regular physiotherapy and other maintenance therapies stop, often leading to a decline in physical function and participation. **NICE guidelines and standards^{vi} recommend an annual review for every adult with CP** so that the slow, steady decline experienced by many people with CP can be identified and supported with early intervention, as highlighted by Paul Maynard MP in his adjournment debate in the House of Commons in March 2023^{vii}.

People with cerebral palsy have no specialist services to transition into. Cerebral Palsy Scotland runs one of the few specialist adult services in the UK^{viii}. Local statutory services are not being held to account for failing to implement or even take note of the NICE guidelines and standards for the treatment of adults with cerebral palsy. Currently therefore there is a lack of specialist services for people with cerebral palsy to transition into. Responsibility for managing care transfers to non-specialist primary care, in exactly the same way as any other adult, with no support for ongoing maintenance issue, let alone the unique challenges faced by this population including, pain management, mobility issues, premature ageing and muscular-skeletal problems.

Disability Evidence and Data Improvement Programme

We believe that people with cerebral palsy are invisible to service providers because there is no means to collect robust data on this population. We understand NHS England's Long-Term Plan identifies digital transformation as a priority; a key aspect of which is the procurement of a federated data platform. We hope that this will lead to better identification of conditions like cerebral palsy across all services and in primary, secondary and community care settings. We urge departments to work closely with the devolved administration on these issues so that learning can be shared. For example, we encourage colleagues to look at the Scottish Government's Framework for Action for Neurological Conditions and the challenges of gathering prevalence data and the development of a Scottish Epilepsy Register^{ix}.

ⁱ <https://worldcpday.org/wp-content/uploads/2021/08/CPA-Poster-2.pdf>

ⁱⁱ <https://pubmed.ncbi.nlm.nih.gov/34548712/>

ⁱⁱⁱ <https://commonslibrary.parliament.uk/research-briefings/cbp-9602/#:~:text=How%20many%20people%20have%20a,24%25%20of%20the%20total%20population.>

^{iv} <https://eprints.gla.ac.uk/111253/> and <https://eprints.gla.ac.uk/111252/>

^v <https://cpsport.org/frame-running/>

^{vi} <https://www.nice.org.uk/guidance/ng119> and <https://www.nice.org.uk/guidance/qs191>

^{vii} <https://hansard.parliament.uk/commons/2023-03-30/debates/CF808DB3-21D7-4FE7-BB54-C683DB579473/CerebralPalsyAdultCareTransition>

^{viii} <https://cerebralpalsyScotland.org.uk/how-we-help/for-adults-individual-therapy/how-we-help-adults/>

^{ix} <https://www.gov.scot/publications/neurological-care-support-framework-action-2020-2025-midpoint-progress-report/pages/4/>