



cerebral  
palsy  
scotland

## Cerebral Palsy Scotland community survey, January-March 2023

### Key insights

November 2023

## Cerebral Palsy Scotland community survey – key insights

### Background

Between January-March 2023, Cerebral Palsy Scotland ran a survey in order to get an insight into what services were being used by the cerebral palsy community, how easy these services were to access, the issues that mattered to them, and challenges they were currently facing. We also asked for feedback on our own services too. Our overall aim was to use all of these insights to shape our own services now and in the future, and to make them as useful as possible to the cerebral palsy community.

### 1. Who responded to the survey?

- 120 adults and 14 children responded to the survey
- 36 adults and five children identified themselves as a person with cerebral palsy
- 87 said they were an unpaid carer for someone with cerebral palsy, and/or had a friend or family member with cerebral palsy
- Eight people said they were an education, health or care professional
- Of the adult respondents, most were from NHS Greater Glasgow and Clyde (34%), NHS Grampian (13%) and NHS Lanarkshire (12%).
- The age range of adult respondents was: 18-24 (3%); 25-44 (50%); 45-64 (41%); 65+ (8%)

### 2. Adults are struggling to access therapy and other relevant services

- 43% of adults said they were not accessing therapy for their cerebral palsy
- When asked if there was a therapy they would benefit from, the three most popular responses were:
  - Physiotherapy (34%)
  - Hydrotherapy (19%)
  - Mental health support (12%)
- When asked what was preventing them from accessing services, the most common reasons were:
  - Lack of resources and services (37%)
  - Cost (22%)

Outwith Cerebral Palsy Scotland, the survey revealed that adults were struggling to access, or were not aware of, a variety of relevant services/support:

- 74% could not access psychological support elsewhere
- 74% could not access group-based therapy elsewhere
- 69% could not access social events elsewhere
- 63% were not aware of campaigning on behalf of people with cerebral palsy elsewhere
- 58% could not access signposting to other services elsewhere
- 55% were not aware of awareness raising about cerebral palsy elsewhere
- 39% could not access individual therapy

### 3. People want Cerebral Palsy Scotland to offer a range of services, and see therapy as our most useful service

A majority of respondents said it was ‘extremely important’ that Cerebral Palsy Scotland offer:

- Individual therapy (73%)
- Psychological support (63%)
- Information about cerebral palsy (68%)
- Awareness raising about cerebral palsy (78%)
- Signposting to other services (63%)
- Campaigning on behalf of people with cerebral palsy (73%)

A majority of respondents thought it was ‘important’ that Cerebral Palsy Scotland offer:

- Social events (44%)
- Group-based therapy or support (42%)

Most respondents felt that therapy was our most useful service

- 54% of those surveyed felt therapy was our most useful service
- 11% felt groups were the most useful
- 11% felt support and advice was the most useful
- 9% felt that psychological support was the most useful

For people who felt groups were important to them:

- The majority (41%) want to see Cerebral Palsy Scotland run social groups, and especially groups for people of a similar age/peer group.
- A smaller percentage (16%) would like a group to support parents/carers.

When asked the question, ‘Would you like to tell us anything else about our services?’ the following themes emerged:

- 32% commented positively on their experience of the services they received at Cerebral Palsy Scotland
- 13% commented that distance was a barrier to them accessing Cerebral Palsy Scotland services, and wanted our services to be available closer to their communities.
- 10% commented positively on Cerebral Palsy Scotland’s adult services

## 4. Things people wished others knew about cerebral palsy

A range of views were expressed when respondents were asked the question, “What are the things you wish other people knew about cerebral palsy? The three most common themes that people wanted others to know about cerebral palsy were:

- Facts about cerebral palsy, especially the diversity of the condition (44%)

“How common it is, relative to other disabilities. That it's a spectrum with everyone affected differently.”

“That not all cerebral palsy is on severe spectrum and not all of use wheelchairs or aids. To educate others about the hidden aspects of cerebral palsy such as pain, bowel/bladders issues, sleep issues, fatigue, mental health issues.”

“It is lifelong, not static, varies between individuals, progress and development are still possible.”

- That the condition doesn’t define you, and you should be treated as an equal individual to non-disabled people (22%)

“Just that it doesn't define the child... Anything is possible for them.”

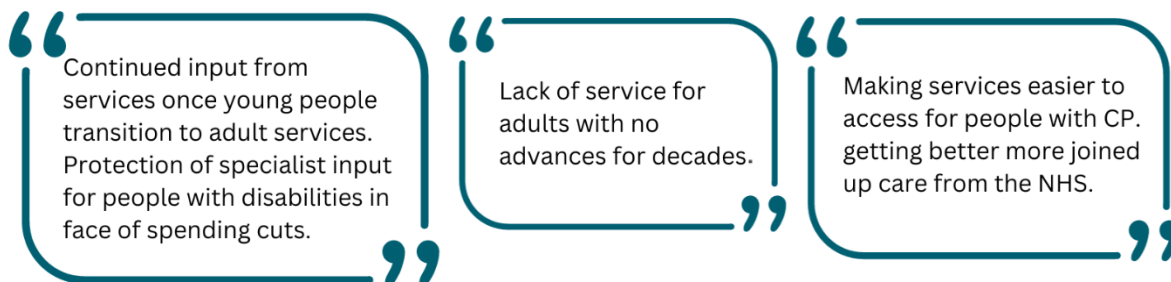
“We are normal and have a place in society.”

“We are human.”

- For others to understand the challenges faced by those with cerebral palsy, and the need for more support (20%)

## 5. Lack of health and care services and support is a key issue for the cerebral palsy community

When asked, 'What would be the most important issue for Cerebral Palsy Scotland to campaign and/or raise awareness on?' 44% said they wanted Cerebral Palsy Scotland to campaign for more health care support and services for people with cerebral palsy.



Just over half (53%) of all respondents felt that a lack of support and services, including a lack of funding within the NHS, was the most important issue they will face in 2023.





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