Cerebral Palsy Scotland Community Survey, January-March 2025

Key insights

March 2025

Cerebral Palsy Scotland Community Survey – key insights

Background

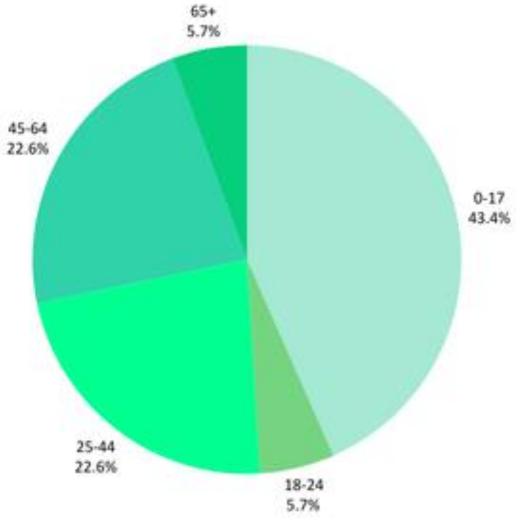
Between January-March 2025, Cerebral Palsy Scotland ran a survey to get insight into:

- the key challenges facing the cerebral palsy community
- feedback on the charity's services

We will use these insights to develop and improve our services and to inform our campaigning work.

1. Information about the respondents

- 63 people responded to the survey. Of those:
    - 33% identified themselves as a person with cerebral palsy
    - 49% identified as a parent carer, family member of a person with cerebral palsy, or an unpaid carer.
    - 14% identified as health or education professionals.
- Respondents came from a good spread of local authority areas, with 24 out of 32 local authorities represented in the survey.
- People with cerebral palsy of all ages were represented in the survey:



- When asked if the person with cerebral palsy had a learning difficulty or learning disability, 45% said yes, 39% said no, and 16% didn't know.

2. Support for people with cerebral palsy is limited

The survey highlighted that people were struggling to access a range of condition-specific support. Outside of Cerebral Palsy Scotland:

- 91% were not able to access psychological support for their cerebral palsy
- 81% were not able to access groups for people with cerebral palsy
- 45% were not able to access individual therapy

3. People want Cerebral Palsy Scotland to offer a range of services, and see awareness raising and information sharing as our most useful services

Respondents said it was ‘extremely important’ or ‘important' that Cerebral Palsy Scotland offer:

- Awareness raising about cerebral palsy (96%)
- Information about cerebral palsy (92%)
- General advice/support from our Cerebral Palsy Support Coordinator (92%)
- Training and webinars for professionals that support people with cerebral palsy (92%)
- In-person therapy (90%)
- Training and webinars for people with cerebral palsy and their carers (88%)
- Campaigning (88%)
- Virtual therapy (84%)
- Psychological support relating to managing their cerebral palsy (83%)
- Social events (82%)
- Group based therapy or support (79%)

4. Cerebral Palsy Scotland’s services are highly valued

Respondents showed a high level of appreciation for Cerebral Palsy Scotland and the services provided.

> One of the most important things to me is being able to have therapy with Cerebral Palsy Scotland’s specialist therapists and also being reassured that I do have some place where I can feel safe and belong, for the first time in a long time.

> Your recent outreach work in Aberdeenshire was a massive help. It allowed [me] as a parent to understand my son’s CP in a much more constructive way, and it really improved my son’s outlook on living with CP and gave us both a focus going forward. Thank you for coming up to us.

> If not for Cerebral Palsy Scotland there would be not care at all. This...group provides the majority of treatment available. This is unusual and impressive.

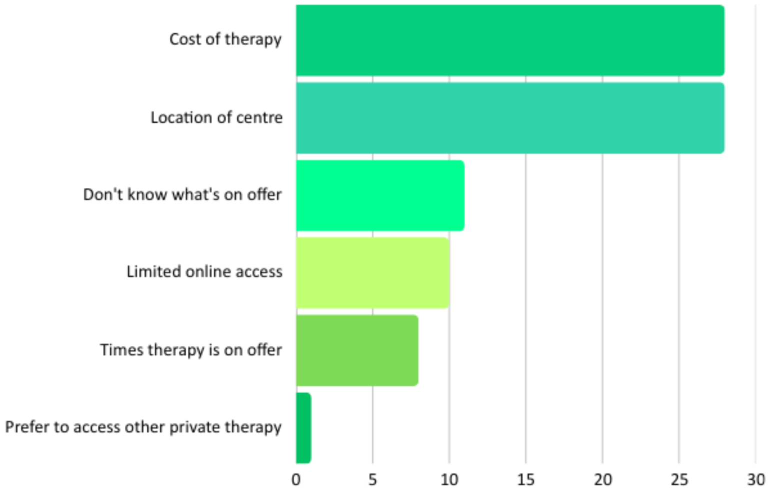
> Your services that I've used are first class.

> Its a unique service which has a good understanding [of] CP and its affects as you grow older and life skills become more challenging due to declining abilities

> Cerebral Palsy Scotland gives confidence and understanding of all things CP. Very much our safety net for guidance and advice.

5. Barriers to accessing Cerebral Palsy Scotland services

The two main barriers to accessing Cerebral Palsy Scotland services identified by respondents were: cost of therapy and location of the centre.



6. 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:

- That **people were more educated about cerebral palsy** as a condition (20 comments) – including the following:
    - Diversity of the condition (five comments)
    - That cerebral palsy is a lifelong condition, and that the condition impacts differently as people age (five comments)
    - Not everyone has a learning disability (five comments)
    - Tiredness (two comments)
    - Pain (two comments)

- That the **condition doesn't define you**, that you should be treated as an equal individual to non-disabled people (seven comments)

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

> I'd like people to know that cerebral palsy does definitely change as we get older. Therapy that is lifelong is essential for our physical and psychological health. Also I wish people would remember that not everyone with CP has a developmental or learning disability.

> There is widespread stigma / ableism in society that those of us with CP are inferior.

> That people with any disability [are] more than their disability and should not be underestimated.

> I wish people would see past the wheelchair and see the soul that [my daughter] is. It can be a struggle at time to get [professionals] to see her. Really see her. The soon to be teenage lass, whose body just happens to move differently.

7. What do the cerebral palsy community want Cerebral Palsy Scotland to campaign on?

When asked, ‘What would be the most important issue for Cerebral Palsy Scotland to campaign and/or raise awareness on?’ the most common themes that emerged were:

- **Lack of health care services and therapy** support. The need for more funding so there can be better access to specialist services. (twelve comments)
- **Awareness raising** about cerebral palsy and the impacts of cerebral palsy. (ten comments)
- **Lack of access** across society, including: transport, holiday accommodation, toilets, and children’s clubs. (seven comments)
- **Positive messages** around how people with cerebral palsy can achieve with the right support (three comments)

> How little funding there actually is to support people affected by cerebral palsy. How many people actually are affected by it in Scotland.

> Tackling health / social / education / employment inequalities.

> CP treatment should be given more funding and treatment standards and expectations should be taught in general practice.

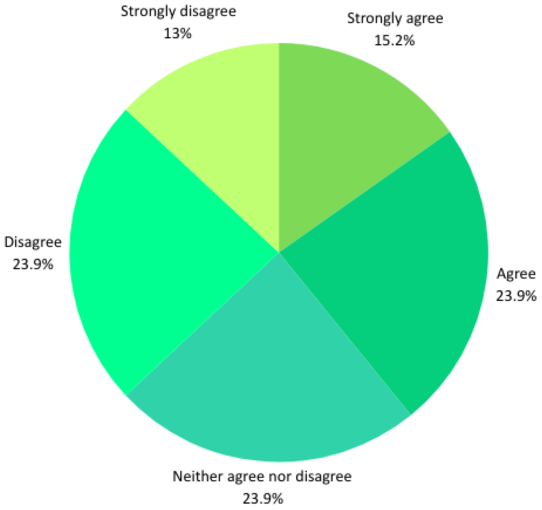
> The lack of services/provision for young people transitioning to adulthood.

> Accessibility everywhere- the right to go wherever [we] want!

> The fact that services are going back the way. Services being cut. Support being cut.

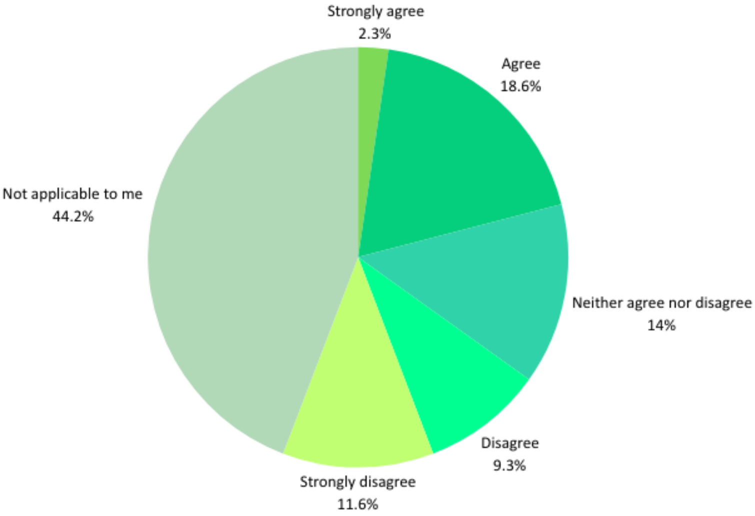
8. Health and care in the community

There was no clear consensus to the question, ‘To what extent would you agree or disagree with the following statement: ‘”The health professionals that work with me/my child in the community have the knowledge and skills to appropriately support me/my child”’:



There was also a lack of consensus around opinion on social care support, including Self-Directed Support, with this topic not being applicable to the majority of respondents.

When asked, ‘If you receive social care support / Self-directed Support (SDS), to what extent would you agree or disagree with the following statement: “The package of care support that the child or adult with cerebral palsy currently receives meets their needs”’:



9. Conclusion

Taken as a whole, the survey showed that respondents greatly valued Cerebral Palsy Scotland.

It was clearly seen that many of the services Cerebral Palsy Scotland offers are hard to find or not available elsewhere, and that the lack of condition-specific health care services for people with cerebral palsy was a key concern.

The survey showed that respondents faced a range of challenges and barriers in day-to-day life. In particular, the need for wider society to have a greater understanding and awareness of the condition, and how it affects people differently, also came across very strongly.

When comparing findings in this survey to previous surveys carried out by Cerebral Palsy Scotland, the findings and challenges faced by the community remain consistent, showing that little has improved for the population.

Cerebral Palsy Scotland is committed to listening to feedback from the community. We will continue to work to develop our services to ensure they meet people’s needs, and to reflect the community’s views in our policy and campaigning work.

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