



cerebral
palsy
scotland

Social care and Self-Directed support for people with cerebral palsy in Scotland: Your experience

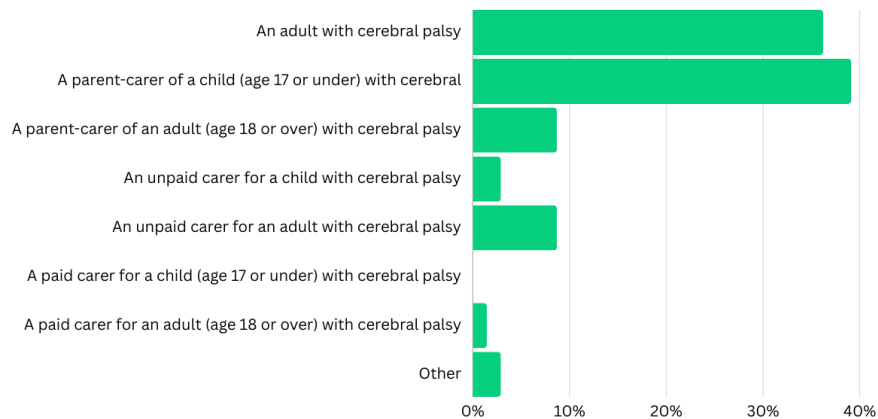
February 2024

Introduction

Between December 2023 – January 2024, we asked the cerebral palsy community in Scotland to share their experiences of social care and Self-Directed Support through completing a survey.

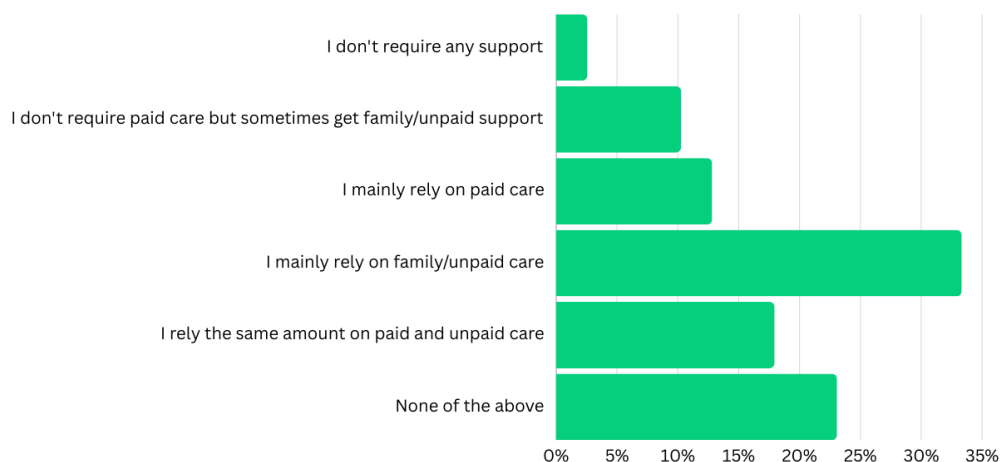
Who completed the survey?

In total, 69 people completed our survey.



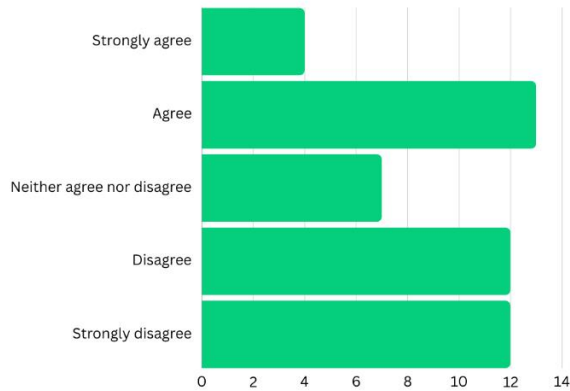
Many adults with cerebral palsy are relying mainly on family and unpaid carers to support them.

When adults with cerebral palsy or their carers were asked to pick the statement that best applies to them:



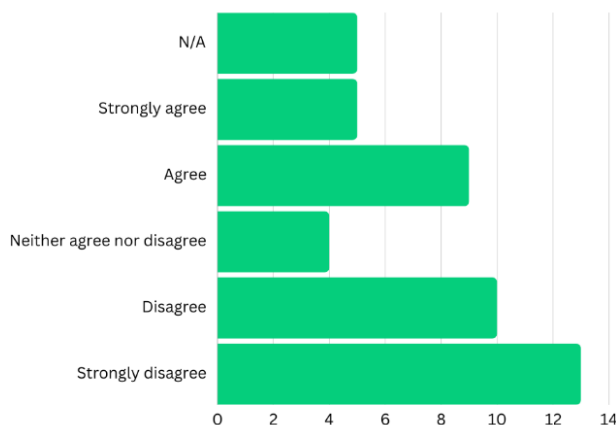
Half (50%) of respondents were dissatisfied with their experience of being assessed for social care, while 35% were satisfied.

When asked, ‘The child or adult with cerebral palsy had a positive experience when they were being assessed for their package of support.’:



Half (50%) of respondents felt that their care package doesn't meet their needs, while 31% felt that it does.

When asked, ‘The package of care support that the child or adult with cerebral palsy currently receives meets their needs.’:



Key criticisms of the social care system and Self-Directed Support

The reasons people gave for feeling dissatisfied with their assessment:

- The process is not person-centred or flexible enough – it is ‘one size fits all’
- The process is too slow
- The process is overly intrusive
- People with cerebral palsy and their carers can feel unfairly judged by professionals, or made to feel guilty for asking for help
- People with cerebral palsy can feel misunderstood by professionals
- The assessment process was not handled as professionally as expected
- Some felt that the physical and mental impact of caring on carers themselves should be better recognised and understood by professionals
- Some people feel they have wrongly been assessed as not needing support

The reasons people gave for feeling their care package didn’t meet their needs:

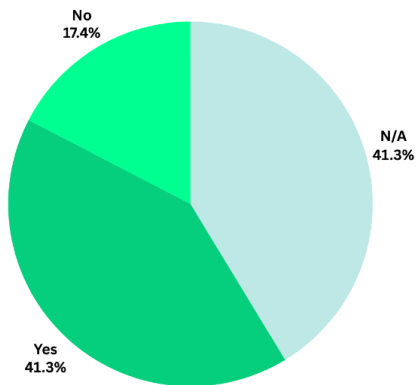
- People are not getting enough hours of care, or enough money, to fully meet their needs.
- There are not enough services available in the community to meet people’s needs, even if funds are available
- Problems with staff recruitment meant people couldn’t use all of their support budget, or in some cases couldn’t use any of it
- What the person is allowed to spend their support budget on is too limited/inflexible, and consequently they don’t feel in control of their budget
- The person or family are confused and unsure what they are entitled to

Overarching criticisms of the social care system and Self-Directed Support

- There isn’t enough money ‘in the system’
- The system needs overhauled and is not fit for purpose
- The system of SDS is daunting, complex and should be easier to navigate with more support offered
- The system only responds when people are pushed beyond their limits, placing further pressure on services
- The system as a whole needs to be more person-centred, more flexible and less judgemental
- Challenges in the system are affecting people’s and carers’ mental health

Recruiting enough – or any – paid carers is the biggest concern amongst respondents

When asked, ‘Has the child or adult with cerebral palsy’s care support ever been interrupted or stopped because of a failure to recruit Personal Assistants/carers?’, 41% said that it had:

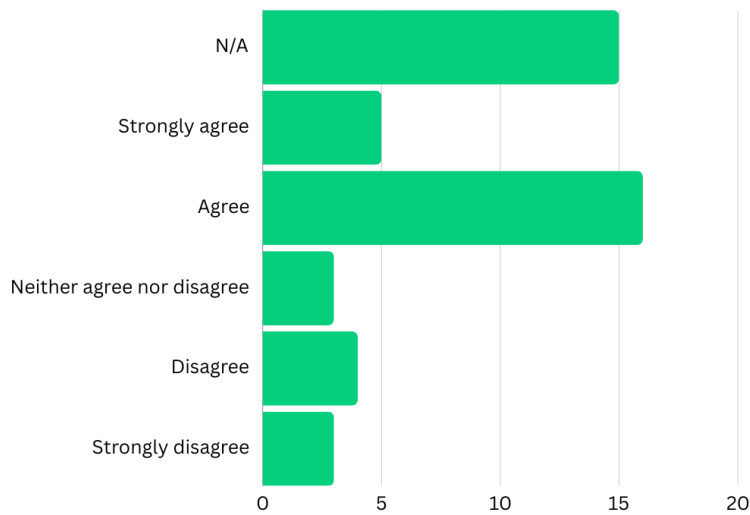


Specific challenges around recruitment of paid carers noted were:

- People are faced with a support budget they can't spend as they can't recruit enough staff, or any staff at all
- Frequent changes to a staff team has an impact on care and increases time given to training
- It can be hard to recruit staff when the person is only awarded a small number of hours of paid care each week
- No replacement staff are available when a paid carer is off sick
- Lack of staff means the person has to move back home repeatedly – or permanently – from their supported accommodation
- The person has had to take time off work due to lack of paid carers
- The rate of pay offered to paid carers makes it hard to recruit good quality staff

Most people feel that their paid carers have the right knowledge and skills to do the job.

When asked, 'The child or adult with cerebral palsy's paid Personal Assistants/carers have the knowledge and skills to appropriately support them.':



Some respondents noted they found it challenging that they/their family were responsible for training staff. It was also noted by some respondents that it was difficult to find training courses available to put staff on.



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