# Make people with cerebral palsy <u>count</u> Pledge to improve services



Cerebral palsy affects a person's ability to control their movement, posture and balance. No two people experience cerebral palsy in the same way.

As a person with cerebral palsy grows, they can develop secondary issues which can affect a person's physical abilities over time. People can also experience problems with pain and fatigue as they grow older.

Through access to the right support and good services, people with cerebral palsy can have an equal opportunity to succeed and reach their full potential.



## Poor data is leading to poor services

There is no clear picture of who has cerebral palsy and where they live.	<b>e</b> This means that services cannot be well planned.
No data is collected on adults with cerebral palsy.	<b>O</b> There are no specialist healthcare services for adults with cerebral palsy.
The best existing source of data for children with cerebral palsy - the Cerebral Palsy Integrated Pathway (CPIP) - is incomplete.	Children aren't getting enough support, and then experience a 'cliff edge' of care when they transition into adult services.

We can improve services for people with cerebral palsy...



## Make people with cerebral palsy <u>count</u> by:

- Continue to fund and expand the CPIP database to cover all children in the UK.
   Integrated Care Boards (ICBs) must co-ordinate primary and secondary health and social care data in order to gather information on how people with cerebral palsy use services.
   Improve care and transition to adult services:

   Develop a clear understanding of the numbers of children with cerebral palsy and identification of their health, care and educational needs
   Integrated Care Systems (ICSs) must effectively implement the existing NICE guidelines: 'Cerebral palsy in adults' and 'Cerebral palsy in under 25s: assessment and management'
   The Department of Health and Social Care must ring-fence funding to ICSs to enable them to develop specialist services
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Government should work with practitioners, academics and those with lived experience to commission and fund research to understand the impact of lack of support and services for this ignored population.

#### **About Cerebral Palsy Scotland**

We're a charity that improves the lives of children and adults with cerebral palsy through specialist therapy, support and information.

We're ambitious for people with cerebral palsy. For over 25 years our therapists have worked alongside people with cerebral palsy, their families and carers, helping them develop practical skills which transform daily life.

#### We hope that you will support this campaign.

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