



Barriers for adults with Cerebral Palsy on achieving full life participation: access to healthcare services and progressing at work



All-Party Parliamentary Group on

Cerebral Palsy

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Foreword

Dear Colleagues,

We are delighted to commend to you the third report from the All-Party Parliamentary Group on Cerebral Palsy, produced with the engagement, assistance, and support of Adult Cerebral Palsy Hub and Scope, as well as clinicians and members of the adult Cerebral Palsy community.

Cerebral Palsy is a lifelong condition, and we hope that this report emphasises the crucial need to refocus attention on barriers to achieving full life participation for those living with it.

The purpose of setting up the APPG was to ensure that those with the condition and their families receive the earliest possible interventions, the best pathways of care throughout their lives, and the brightest futures.

Our first report discussed the need for effective, early intervention to improve life outcomes and minimise secondary complications, and our second report examined best practice in Education, Health and Care Plans (EHCPs), Teaching, and Learning for Children with Cerebral Palsy which our third and fourth APPG meetings examined in detail.

This third report focusses on access to healthcare services and progressing work for people living with Cerebral Palsy. The COVID-19 pandemic has highlighted both opportunities and barriers in both areas, but we also must not let the pandemic distract from long-standing problems that need to be addressed.

We are immensely grateful to all those who attended the fifth and sixth meetings of the APPG to examine these topics in detail, and to those who submitted the evidence that provides the backbone to this report.

As Members of Parliament with lived experience of Cerebral Palsy, we hope Government will engage with the APPG's recommendations and work with us to provide quality provision and specialist care throughout life for those living with cerebral palsy to ensure they have the best life chances possible.

We would like to invite you to work with us to keep improving cerebral palsy provision for the better by engaging with Ministers on our recommendations and by joining the APPG to help shape our work.

If you would like to join the APPG, please email the secretariat at CerebralPalsyAPPG@connectpa.co.uk for more information.

With best wishes,



Mary Kelly Foy MP
Co-Chair of the APPG on Cerebral Palsy
Member of Parliament for City of Durham



Paul Maynard MP
Co-Chair of the APPG on Cerebral Palsy
Member of Parliament for Blackpool North & Cleveleys



Cerebral Palsy is a lifelong condition. We deserve lifelong support."
Claire Duffet, an adult living with Carebral Palsy

Introduction

Adults living with Cerebral Palsy face several challenges as they navigate their lives. They live with a fluctuating, lifelong condition with the needs of each person requiring carefully co-ordinated specialist care and support to ensure they can live a full life. There is a common misconception that Cerebral Palsy is a paediatric condition, however, 90% of children with Cerebral Palsy reach adulthood and find themselves at a cliff-edge, without the support they had relied upon for their first 18 years of life.

Many of those moving from paediatric services into adulthood face this cliff-edge and loss of support. Provision of adult services is inconsistent across the country and where a transition does take place, it is rarely smooth.

These factors mean that the 130,000 adults with Cerebral Palsy in the UK face inconsistencies in their experiences and outcomes from services, stemming from a lack of understanding of their condition and the differing effects it has on their individual lives. Compounding this problem are the barriers people with Cerebral Palsy face in accessing services which can provide them with independence.

In our third report exploring Cerebral Palsy as a lifelong condition, the All-Party Parliamentary Group on Cerebral Palsy will focus on two key areas. Firstly, we examine the transition from childhood into maturity, and how this impacts the ability of adults with Cerebral Palsy to access healthcare services. Access to specialist health and social services is the core for enabling adults with Cerebral Palsy to live their lives as fully as possible.

Secondly, we assess the barriers facing the adult Cerebral Palsy community in entering, remaining, and progressing through the world of work. Our work dovetails with the wider issue of employment and economic opportunities for the entire disabled community but presses for recognition of the specific and varying needs of those living with Cerebral Palsy. Above all else, working to overcome the barriers adults with Cerebral Palsy face cannot be siloed into a single policy area. The APPG has chosen to focus upon healthcare and work in this report because these are two of the most important pillars in a person's full life. However, equality of access and opportunity in life for the tens of thousands of people living with Cerebral Palsy cuts across all policy areas.

We are extremely grateful to the experts, clinicians, educators, specialists, politicians, and all those with lived experience and their families who have responded to our call for evidence. The high level

of interest, including the stark reality of the personal testimony provided by the adult Cerebral Palsy community, speaks to the urgent need to remove barriers as soon as possible.

Themes touched on the ten recommendations in this report will be explored in further work we do exploring the impact of Cerebral Palsy as a lifelong condition. The foundation of the actions we recommend in this report are aimed at supporting deeper changes including improving knowledge of Cerebral Palsy in adulthood; better understanding its effects and how it manifests throughout life; further education and training about the condition; ensuring joined up services are available through specialist roles; and the ready availability of vital support services like lifelong physiotherapy.

Our recommendations have drawn on evidence from all parts of the United Kingdom. With the devolution of healthcare, we recognise that there are different solutions in different parts of the country and different jurisdictions. An example is the provision of a Cerebral Palsy Register in Wales and Northern Ireland, but not in England or Scotland. This is just one case where learning lessons already in play would help in the identification and treatment of adults living with Cerebral Palsy. Our report should be therefore considered UK-wide in its recommendations, especially when it comes to sharing best practice across the UK.

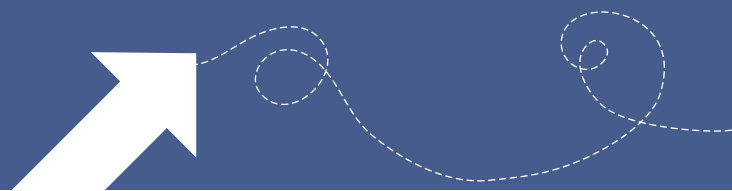
Finally, the recommendations made in this report are an important starting point for addressing barriers encountered by the adult Cerebral Palsy community in accessing healthcare and work. We believe that policymakers, clinicians, and employers should go further and fully support significant steps they can take beyond those set out in this report, considering the fact that every person is different and has different care and support needs.

“When I was very little—too young to really understand, in truth—my mother told me that I would always be treated differently [...] “They don’t care about you. You are an object. A case number. Nothing more. Never rely on them.”
An adult living with Cerebral Palsy

Summary of key recommendations

- 1** NHS England, social care, education, and employment specialists must agree a national service specification for adult Cerebral Palsy to be used to commission dedicated specialist services based on the needs of local populations within the 42 new Integrated Care System areas.
- 2** To support GPs in identifying adults with Cerebral Palsy, the UK-wide Quality and Outcomes Framework (QOF) must be extended to incorporate the creation of general practice-level Cerebral Palsy registers along the lines of the expansion of QOF to learning disabilities. Once identified, adults living with Cerebral Palsy must receive annual medical reviews, whilst improved coding of medical records will support GPs in identifying patients in need of support.
- 3** Training for those working in general medicine, general practice and nursing must specifically cover adults with Cerebral Palsy from an entry level upwards.
- 4** Each Integrated Care System (ICS) area will be required to undertake a gap analysis of existing Cerebral Palsy services for adults against NICE guidance and use the results to inform and guide their local commissioning decisions.
- 5** The Department of Health and Social Care and the Department for Work and Pensions must ringfence funding to ICSs to enable them to develop specialist services and for these services to work in partnership with the working health program at a local level to support individuals on health grounds, as well as accessing and staying in employment.
- 6** The Government should fully utilise the review of Disability Confident to strengthen the criteria employers are required to meet at all levels of the scheme. This would include introducing minimum criteria that employers will have to meet if they are to retain their status as members, for example hiring a certain percentage of disabled people, especially adults living with Cerebral Palsy.
- 7** The National Disability Strategy must create an online advice hub for employers taking part in the Disability Confident employer scheme and provide clear accreditation to those making full use of the service. This hub would allow adults with Cerebral Palsy to share their experiences of their fluctuating conditions to provide guidance for employers in meeting the needs of their staff.
- 8** The reality for those living with fluctuating conditions, such as Cerebral Palsy, to manage their disability while staying in work must be realised in employment rights and procedures. This includes introducing the right to request flexible working from the same employer more than once in calendar year to a maximum of once a month. Employers should also be required provide a written explanation for any decision to reject any request to work flexibly for adults with Cerebral Palsy.
- 9** The current 'Shaping Future Support' Green Paper must improve the employment support offered to adults with Cerebral Palsy through the welfare system. This includes ensuring that DWP work coaches receiving comprehensive training around disability equality and communication skills and being fully informed of the wider support available, especially in relation to employment and training opportunities for adults with Cerebral Palsy.
- 10** Allow disabled people over the age of 24 to access the Government's Kickstart Scheme to provide adults with Cerebral Palsy access to valuable work experience, as well as high quality assistance to support their progression in the workplace and their career.

Postcode lottery of specialist support



The common factor constraining the lives of adults living with Cerebral Palsy is the geographic variations in vital support across the UK. This results in worse health outcomes, lower education and employment participation for individuals, and a substantial economic loss to our country. Life expectancy for adults living with Cerebral Palsy is strongly associated with motor function and feeding skills, but most adults with mild to moderate Cerebral Palsy can expect to live as long as those who do not have Cerebral Palsy.

Sadly, the transition into adolescence and adulthood is often accompanied by a decline in physical function, with 20-50% of people with Cerebral Palsy experiencing deterioration in walking function between 20 and 40 years of age. Despite this, research tells us that 70% of the Cerebral Palsy community possess higher mobility levels and should be fully able to participate in the workforce with the correct support. A radical re-organisation of employment support for people with Cerebral Palsy should be undertaken to allow better targeting on health grounds. Even then, this can only be achieved when there is collaboration between all services, for example: job centres, support organisations, the NHS, social care support organisations, and colleges.

The postcode lottery of support is both a national and a local problem. Analysis from the Northern Ireland Cerebral Palsy Register has shown that the prevalence of Cerebral Palsy in adults is comparable to that of Multiple Sclerosis or Parkinson's Disease. However, health services for adults with Cerebral Palsy fall short of what is needed in relative terms.

Evidence given by The Association of Paediatric Chartered Physiotherapists to the APPG reports that:

'Health services for adults with Cerebral Palsy are less well-developed, not equitable across the UK and do not meet current NICE guidelines.'

Maintaining the status quo is not acceptable. The full implementation of the NICE guidelines must be a baseline and, at the very least, this should be expected from NHS leaders and clinicians.

However, this is not currently the case for patients with Cerebral Palsy accessing our NHS services. Sarah Cooper, a member of the adult Cerebral Palsy community, wrote in her submission about how she had shared the NICE guidance from 2019 with her GP, who had been unaware of it.

The NICE guidelines provide the most effective template for delivering joined-up healthcare provision and providing equal access to healthcare services across the country. We question why these measures are not being implemented and why it is being left to patients to inform clinicians of them. NHS England, NICE, and the emerging ICSs must provide leadership in this vital area.

In her evidence to the APPG, Anne Scott, who lives with Cerebral Palsy, underlined how a lack of clinical support has impacted her life opportunities:

'There were no Cerebral Palsy specialists in Cornwall [...] I was 30 before I saw a specialist in Cerebral Palsy, and he was in Taunton, two counties away and three hours away by train. [...] He completely contradicted the previous specialist's advice about my muscle relaxants, leaving me feeling confused and bulldozed [...] Who am I supposed to believe?'

Ms Scott's story is not atypical. A UK-wide survey of 162 adults with CP, aged 18-74 years, living in the UK and Ireland asked participants to describe how and why they accessed and used physiotherapy services. Their results found that physiotherapy services in the UK do not currently meet the needs of adults with CP.

Key findings included:

- 90% of participants reported needing to see a physiotherapist.
- Only 35% of participants had been able to access these physiotherapy services.
- Adults with mobility decline were less likely to receive the physiotherapy they needed.
- Only 21% of participants reported being satisfied with the availability of physiotherapy services.
- Only 27% of participants reported being satisfied with the quality of physiotherapy services.
- Forty-three percent (43%) of participants reported that the physiotherapists they consulted were not usually experienced in working with adults with CP.

Most participants (62%) sought out physiotherapy for mobility decline, with just over 80% of participants reporting a decline in mobility since turning 18 years of age. 63% of participants reported experiencing a decline in mobility in the past year. This underlines the danger of a cliff-edge in support as children with Cerebral Palsy transition into being young adults living with Cerebral Palsy. Many adults living with Cerebral Palsy only need targeted interventions well into maturity.

Postcode lottery of specialist support

Dean O'Shea, a patient in his fifties from Blackpool living with Diplegia Cerebral Palsy conveyed his difficulties in accessing local specialist Cerebral Palsy services. Able to walk independently until he was 39, Mr. O'Shea required access to specialist services after a fall. He provided a breakdown of the specialisms that he as an adult living with Cerebral Palsy would need to be provided in his area, which included:

- Consultants
- Nurses
- Trauma Nurses
- Neuro Physiotherapists/General Physiotherapists
- Occupational Therapists
- Speech and Language Therapists
- Podiatry
- Surgical Appliances
- Orthotists
- Dietitians
- Hydrotherapy
- Mental Health Nurses
- Sensory Impairment specialists
- Urology, continence and feeding

Mr. O'Shea's case shows complications can arise when living with a lifelong condition, even after years of independent living. Adults living with Cerebral Palsy must have the option of accessing specialist services from the age of 18, to address this cliff-edge moving into adulthood.

The necessary services exist to support adults with Cerebral Palsy, including neuro-physiotherapy and neurology, but only in patches around the country. A common thread is lacking to connect them to each other and to those who need them.

A need to connect disparate areas of service provision was experienced by 31-year-old Sophie Buckley. Despite primarily needing social care support, she instead became more reliant on the NHS. She reflected:

'Social care did have the potential to meet all my needs and delay my need to have input from the NHS. If my needs were addressed at the age of 18, I could have had better mobility, less pain, and less medication.'

To deliver joined-up service provision, **NHS England, social care, education, and employment specialists must agree a national service specification for adult Cerebral Palsy to be used to commission dedicated specialist services based on the needs of local populations within the 42 new Integrated Care System areas.**

Bringing together essential healthcare services would remove many barriers in life faced by adults living with Cerebral Palsy.

In agreeing a new national specification, NHS leaders and clinicians need to end the separation of neuro and musculoskeletal knowledge within the Health Service. As a neuro-musculoskeletal condition, those living with Cerebral Palsy need easy and ready access to both areas. Investing money into joined-up service provision will help those adults living with a lifelong condition and save vital resources down the line.

Commissioning decisions relating to adults living with Cerebral Palsy must also be patient-led. The APPG fully supports enhancing learning, training, and understanding of Cerebral Palsy in all health services, but the voice of adults with Cerebral Palsy must be heard in their care. They have the best understanding of their respective conditions from living with it day-to-day.

In her submission to the APPG, Bethany Young, an adult with Cerebral Palsy, called for the '*Paralympic ethos*' to permeate health services to enable adults with Cerebral Palsy to make their own choices. Adults with Cerebral Palsy needed to be empowered with a right of self-referral and a range of options to choose from in their local areas.



We are a generation trying to be heard. Fighting to get things to change for our future generations."

An adult living with Carebral Palsy



“ *The life expectancy of people with Cerebral Palsy is increasing because of advancements in healthcare. Today people with Cerebral Palsy live considerably longer, making them the largest group of people with lifelong impairments in the UK.”*

Dr Sonali Shah, Centre for Research in Ageing and Rehabilitation,
University of Nottingham

“ *The NHS might be free at the point of entry but getting the services and resources required is a continuous battle [for adults with Cerebral Palsy] [...] In this country we are proud of our NHS so why do I continuously hear people say they have had to fight at every turn for themselves or their loved ones.”*

Anthea Dendy, Clinical Physiotherapy Specialist in Neurology

“ *You become 18 and then [all support] stops. But your Cerebral Palsy doesn't disappear when you're 18, but the services seem to stop.”*

Mary, who lives with Cerebral Palsy, age 35

“ *You spend a week trying to get the [GP] appointment then you get the appointment, and you wait another three weeks for that [...] then you wait another three or four months for the physio appointment, and then you find out whether or not it was the right physio or not.”*

Rachel, living with Cerebral Palsy, age 48

“ *Where do I start?” ... it's like this whole big world ... it is just a real like minefield and you just kind of feel like you need someone on your side.”*

Polly, age 30, with lived experience of Cerebral Palsy

“ *Nobody knows where to go. Nobody can say, 'Maybe try them'.”*

Phoebe, age 31, a member of the adult Cerebral Palsy community

Accessing healthcare – the coalface of primary care

Addressing geographic disparities through creating a national specification is only the first step towards addressing the significant barriers adults with Cerebral Palsy face in accessing healthcare.

A lack of clear care pathways means that GPs report that they are not sure where to send patients when they present with difficulties, in contrast to other neurological conditions. This issue is compounded by a lack of Cerebral Palsy specialist clinicians, generating patient dissatisfaction from unnecessary appointments and a lack of clear communication between medical professionals.

Where community services do exist, adults are often excluded on the grounds of age-related criteria. This leaves their GP as the co-ordinator of care, but co-ordinators who, despite their best efforts, often have not been given the specialist knowledge and training to support their patient. The consequences of this for adults with Cerebral Palsy is set out in the lived experiences of those who have given evidence to our inquiry, highlights of which are quoted on the other page.

One case that highlights a lack of understanding of Cerebral Palsy among many GPs is Elizabeth Knowles. She provided the APPG with a letter of complaint she wrote to her GP in which she detailed the 'frustratingly slow process' she had been through to seek treatment. Ms. Knowles pointed out that she received assessments of her condition from her GP that 'painted an unnecessarily bleak picture of my future'. This assessment was later contradicted by her physiotherapist, who offered a brighter prognosis informed by an understanding of her condition.

A lack of insight at GP level is compounded by the failure of the system to allow for regular medical reviews of adults with Cerebral Palsy based on their greater risk of co-morbidities.

Written evidence provided by a consultant Geriatrician and Sub-Dean of Glasgow Medical School, said:

'There is no training about Cerebral Palsy in adults to medical students during their undergraduate training. This extends to the post graduate curriculum in general medicine and general practice.'

One way to support GPs in identifying adults with Cerebral Palsy is to **extend the UK-wide Quality and Outcomes Framework (QOF) to incorporate the creation of general practice-level Cerebral Palsy registers along the lines of the expansion of QOF to learning disabilities.**

Once identified, adults living with the conditions must be guaranteed annual medical reviews to reduce the risk of comorbidities. On the administrative side, improvements in coding on medical records will help GPs identify adult Cerebral Palsy patients among their caseloads.

However, improving identification must come alongside actions to support both GP and adults with Cerebral Palsy. **These should begin during education and training for general medicine, general practice, and nursing from an entry level and above on adults with Cerebral Palsy.**


Leon Taylor, a 46-year-old man born with hemiplegia, emphasised the importance of his 'annual MOT' for referring him on to specialists. Having benefited from his regular medical review, Mr. Taylor must still wait long periods of time to see a specialist, for example, nine months between appointments at a pain management clinic. Improving identification and understanding at the coalface of primary care are important steps towards removing barriers to accessing healthcare.

On top of this, access to ongoing rehabilitation or ability to access timely support during periods of acute need is the primary reason adults living Cerebral Palsy report frustration and dissatisfaction with health services. People with long-term conditions account for 55% of all GP appointments, 68% of all outpatients and emergency admissions and 77% of all inpatient bed days.

Delays in accessing rehabilitation services come with a human cost. Almost 4% of adults with Cerebral Palsy in Northern Ireland died in adulthood before age 39 because they typically had more significant physical impairments and likely required higher levels of health and care provision.

In her testimonial to the APPG, Dr. Jennifer Ryan from the Department of Public Health and Epidemiology at the Royal College of Surgeons in Ireland, Dublin said:

'Adults with Cerebral Palsy are more likely to develop other chronic conditions, such as asthma, stroke, heart disease and arthritis and experience quicker declining mobility when compared with the general population. Many adults with Cerebral Palsy experience pain, depression, and anxiety. Current services for adults with Cerebral Palsy in the UK fall short of NICE guidelines and standards.'



Individuals like Chris Percival, Lizzie Hare, and others living with Cerebral Palsy found that there was a lack of understanding among healthcare professionals about the secondary conditions that adults with Cerebral Palsy must live with, including fatigue. Many only encountered issues when moving from regular medical contact through childhood to sporadic interactions with health services in maturity. For example, Ms Hare believed many GPs she encountered appeared to 'whitewash any secondary problems by saying it is because of [my] Cerebral Palsy.'

These findings are supported by data that compared 1,705 adults with Cerebral Palsy to 5,115 adults without Cerebral Palsy who had the same age, gender and attended the same General Practice. The analysis found that adults living with Cerebral Palsy were at:

- Increased risk of mortality due to respiratory disease and cardiovascular disease;
- Increased risk of bone conditions;
- Increased risk of cardiovascular disease;
- Increased risk of chronic respiratory disease;
- Increased risk of mental disorders;
- Increased risk of falls.

Adults with Cerebral Palsy are more likely to develop several potentially preventable conditions compared to adults without Cerebral Palsy. However, these could be addressed by putting in place annual medical reviews.

There is also evidence that the physical changes associated with secondary ageing experienced by people ageing with Cerebral Palsy are unanticipated by individuals, their families, and the medical profession. In turn, this can lead to a period of anxiety and stress. People are unprepared for the secondary effects of ageing with Cerebral Palsy and there is a general lack of knowledge about the process.

North of the border, the charity Cerebral Palsy Scotland has been piloting clinical psychological support with

Cerebral Palsy service users presenting with additional emotional/psychological distress. A common factor reported is the significant negative impact living with Cerebral Palsy and its associated challenges has on their overall sense of wellbeing. The APPG wishes to see such services made available in other parts of the UK.

Other adults living with Cerebral Palsy have told us of their frustration as care pathways that were previously open to them have been lost overtime. One indicated this was the case with podiatry and the long-term disabilities neurological care pathway, further adding:

'As a complex need patient, I have found I need to go out of my own area as I was not being served in my locality. However, with the services being closed for so long things are just starting to get going again.'

A 60-year-old man with lived experience of Cerebral Palsy outlined in his submission how the lack of access to NHS services in his area meant 'going private was my only choice'.

Similarly, Margaret Foster reports that she was forced to turn to the voluntary sector when she could not access physiotherapy on the National Health Service after her discharge from hospital, highlighting the importance of aftercare services to adults with Cerebral Palsy.

Another adult living with Cerebral Palsy, a 35-year-old woman, provided a detailed breakdown of the service gaps she had encountered in seeking treatment as an adult, including no provision of physiotherapy services for her from the age of 16 until she was 20. In addition to physiotherapy, she requires regular access to occupational therapy, hydrotherapy, orthotics, wheelchair services and gait analysis. Her suggestion of shifting emphasis in the NHS away from treatment and discharge to prevention whilst improving long-term oversight, aligns perfectly with moving more care out of hospital settings and into communities, as outlined the NHS Long Term Plan.

“

[My GP] does not understand the different types of pain I live with and did not treat them properly. I have been in pain since I was 20. It wasn't until I went to him in utter despair, saying, 'I'm in so much pain I am just waiting until I'm old enough to die,' that he referred me to someone with the knowledge to treat my spasticity."

A member of the adult Cerebral Palsy community

Accessing healthcare – the coalface of primary care

In her research work on Cerebral Palsy and Transition across the South East, Susie Turner, a Clinical Specialist Paediatric Physiotherapist from the Evelina London Children's Hospital, found there were 'significant gaps in meeting the relevant NICE quality statements' for those living with Cerebral Palsy moving into adulthood. This included inconsistencies and challenges with developing a personal folder for a patient, providing an annual meeting on transition for patients and providing a named worker.

She went on to say:

'Failure of the transition pathway means many individuals with Cerebral Palsy and their families continue to rely on paediatric services or end up being discharged into the unknown [...] Joint working between children's and adults' services is required to strengthen the pathway and access the expertise of each service.'

In their submission to the APPG, the British Society for Surgery in Cerebral Palsy conceded that 'there is no reliable evidence to document the extent of the deficit in services for adults with Cerebral Palsy and orthopaedic problems'. However, the weight of personal testimony and existing research points to significant gaps in vital care. It is incumbent upon NHS leaders to improve data collection and research into the challenges encountered by adults with Cerebral Palsy.

A major step towards improving this is the implementation of a Cerebral Palsy Register in England and Scotland, along the lines of what is already in place in Northern Ireland and Wales. This is an essential step that must be immediately undertaken by the Westminster and Holyrood governments.

This point was echoed by Dr. Kimberly Smith, Senior Lecturer in Clinical Health Psychology. She noted that the lack of evidence made it difficult to commission services to cater for the range of mental health issues adults living with Cerebral Palsy are at a higher risk of having.

'The issue with this lack of evidence is that it directly impacts service provision. Without evidence we cannot know which treatments work best, service providers have no evidence-based rationale on which they can commission services and we cannot help improve the psychological wellbeing of this population.'

To address the problems highlighted by case studies referred to above, **each Integrated Care System (ICS) area will be required to undertake a gap analysis of existing Cerebral Palsy services for adults against NICE guidance and use the results to inform their local commissioning decisions.** This must include



My GP does not understand the concept of fatigue as it relates to CP. He thinks my fatigue is caused by my medication [...] I have no confidence that he understands and will remember what I told him."

An adult living with Carebral Palsy

investment in services to support and address associated conditions, including mental health problems arising from the challenges of living with Cerebral Palsy.

The gap analysis should be used by ICSs to establish regional multi-disciplinary Cerebral Palsy clinics for adults of all ages. These would provide access to a range of psychological, physical, and complimentary therapies and are explored in further detail below. Referral to these special centres would be better supported by appointing Disability Access Co-ordinators in both acute and primary care settings to ensure that reasonable adjustments are made.

An integral component of ensuring joined-up care within each ICS area is provision of sufficient neurologists to take responsibility for overall care of adults with Cerebral Palsy. When someone living with Cerebral Palsy is discharged by their paediatrician, they should be handed directly over to a neurologist to remove any cliff-edge in support when they reach the age of 18.

Finally, these gap analyses must deliver a national care pathway for adults with Cerebral Palsy, which was first promised in the NICE guidelines.



My GP provides a valuable service, but GPs don't have knowledge and time to sit with a person with Cerebral Palsy and talk about the condition and the options that are available."

An adult living with Carebral Palsy

Impact of COVID-19 on adults with Cerebral Palsy accessing healthcare

Patchy provision of specialist services and failures to identify the specific needs of adults with Cerebral Palsy in primary care have been compounded by the COVID-19 pandemic.

Because of COVID-19, patients attending hospitals and clinics tend to be alone and lack access to support if they have additional communication needs, including dyslexia and deafness. The hidden gap in care experience by adults with Cerebral Palsy is exacerbated because communication relies not just on the spoken word, but also on non-verbal cues.

In her written submission to the APPG, Jean Martin from Derby details the impacts of COVID-19 on seeking treatment as an adult living with Cerebral Palsy:

'These inequalities have been exacerbated by COVID. Not only have those living with Cerebral Palsy faced higher mortality from COVID infection, they have also faced the impact of reduced access to social care during the pandemic and deconditioning due to reduced access to physiotherapy and specialist physical activity.'

David Smith also pointed out how the impact of the pandemic on the health service affects those with lifelong conditions such as Cerebral Palsy. During lockdown, Mr Smith's wheelchair went in for regular maintenance, but was misplaced. In addition to dealing with a 'slow and unresponsive' complaints system, it took 12 weeks for his replacement chair to arrive.

We have been living through exceptional times, including the NHS, but these examples represent how the pandemic has affected the support services that are essential for adults with Cerebral Palsy to ensure they can go about their lives.

Considering the findings of the [Health Select Committee in their report on clearing the backlog from the pandemic](#), policy-makers and clinicians should expect long-term issues set out in this report to have been compounded by the pandemic.

As we emerge from the pandemic, the Department of Health and Social Care and the Department for Work and Pensions must ring-fence funding to ICSs to allow them to develop specialist services. These services must work in partnership with the working health program at a local level to support individuals on health grounds as well as accessing and staying in employment.

As part of this, the APPG recommends that each of the 42 ICS areas in England establish a specialist multi-disciplinary hub to meet the healthcare needs of adults with Cerebral Palsy. These would provide a 'one-stop shop' to address the diverse and multiple healthcare needs required by the adult Cerebral Palsy community living within that area.

These centres would work along joined up community services to deliver supported, identified interventions on a local level, including pain management falls and mental health needs.

The APPG believes that the launch of the University College London Hospitals' (UCLH) multidisciplinary Adult Cerebral Palsy service in May 2019 can serve as a starting point for others. This service comprises of:

- A weekly multidisciplinary assessment clinic.
- A twice monthly botulinum toxin clinic.
- An ad hoc transition clinics and outreach support.
- Nurse led telephone clinics and key worker role.
- Physiotherapy, occupational therapy, speech, and language or inter-disciplinary reviews.
- Psychology input.
- Group work, currently a 3-session fatigue module, but shortly to include pain, social communication, and transition modules.
- Day care and inpatient admissions as needed for tone management.

Supporting this is a team consisting of: two consultant Neurologists providing 1.5 days a week between them; a full-time clinical nurse specialist; a physiotherapist being available three days a week; Occupational Therapists being available two days a week; a day a week of Speech and Therapy and psychology support; and the required administrative support.

Support and services must be available five-days a week and the APPG wishes to see services reach these goals by 2030. However, the UCLH service provides a template that NHS trusts and ICSs can look to begin to deploy existing resources and build a case for expanding these services. All of this depends on smart, intelligence-driven decisions being made at the commissioning level, driven by input from the local adult Cerebral Palsy community.

Crucially, each of the 42 Cerebral Palsy hubs must be accessible and within easy reach of public transport to remove that barrier to adults with Cerebral Palsy accessing healthcare.

Entering, progressing, and thriving in the world of work with Cerebral Palsy

“ There need to be more pathways for people like me living with Cerebral Palsy to succeed in our chosen career.”

Jay Joshi, adult living with Cerebral Palsy

In the first half of this report, we focused on the bedrock of support needed for adults with Cerebral Palsy to overcome barriers in their lives: access to quality, tailored health, and care support. We want to look at what is possible when health and care services enable the aspirations of adults living with Cerebral Palsy in employment and career progression.

A lack of medical support contributed to Karen Watson's decision to accept early retirement from her role within the NHS at the age of 40. Encountering a neuro-physiotherapist later in life put Ms. Watson in contact with somebody who she feels 'understands my condition, but more importantly, she understands me'. However, Ms. Watson lost out another twenty years of progression in a job she loved. This is just one case where success within work for adults with Cerebral Palsy depends on access to vital support services.

In his evidence, Tim Martin highlighted the extraordinary capabilities that members of the adult Cerebral Palsy community bring to the workplace, but also the importance of the appropriate medical support during employment. Mr. Martin worked for over 40 years rising to become a payroll manager. Yet he missed out on regular physiotherapy, orthotics, and other improved treatments that would have benefited him. Mr. Martin's example highlights the frustrations that adults with Cerebral Palsy experience when lacking access to services and treatments to empower them in the workplace.

Moreover, Cerebral Palsy has a significant economic cost alongside the ongoing health and social care costs. This includes the direct costs of providing support to people with Cerebral Palsy and productivity costs caused by people with Cerebral Palsy being more likely to never enter work or leave earlier than others.


The economic case for improving services for adults with Cerebral Palsy is the same as better services for people with mental health problems, learning disabilities or long-term physical health conditions. If services are improved, people will be able to stay more active and independent longer. This will in turn benefit wider society.

The economic benefits arising from increased participation and retention of adults in the labour market can be clearly illustrated.

According to research from the charity Adult Cerebral Palsy Hub, new nationwide specialist adult Cerebral Palsy services could cost around £20 million per annum. Under the Government's required 1 to 4 ratio of investment for economic benefit, this would mean £80 million of benefit to justify that spend. This could be achieved if only 4,000 people, or 3% of the adult Cerebral Palsy community, gained or are helped to stay in employment.

“ One choice I made throughout my working career was to work part-time and allow time for my Cerebral Palsy, marriage to another Cerebral Palsy adult and family responsibilities [...] In retirement my pension is smaller, the result of the HR regulations at that time denying the opportunity of part-time employees to pay into the staff pension scheme.”

Mrs Jean Martin, Derby



The situation of adults with Cerebral Palsy forms part of the wider disability employment gap, which has been stuck at close to 30% for nearly a decade.

Support must begin with young people leaving school and seeking to enter the world of work. Careers coaching and CV structuring are assistance to be provided to young adults with Cerebral Palsy as they pursue and explore work opportunities.

As part of this, policymakers must make the most of avenues already being explored, but also be prepared to break new ground.

The Disability Confident Scheme, developed by employers and disabled people's representatives, aims to encourage employers to think differently about disability and take action to improve how they recruit, retain, and develop disabled people, including adults with Cerebral Palsy. Campaigning organisations like Scope have long pressed for an overhaul of the Scheme and the APPG support this call.

The National Disability Strategy should press for the creation of an online advice hub for employers taking part in the Disability Confident employer scheme and provide clear accreditation to those making full use of the service. This hub would allow adults with Cerebral Palsy to share their experiences of their fluctuating conditions to help provide guidance for employers in meeting the needs of their own staff.

Guidance provided by an online advice hub can include making employers aware of the need to have conversations with adults living with Cerebral Palsy in their organisation about how to tailor the requirements of a role to their needs.

Frustrations and barriers encountered in the workplace and in job seeking can manifest in a perceived sense of failure for adults with Cerebral Palsy and can affect their mental health and self-esteem. These are some of the hardest barriers for adults with Cerebral Palsy, but also the most preventable.

It is, therefore, imperative that **the Government uses the review of Disability Confident to strengthen the criteria employers are required to meet at all levels of the scheme, including introducing minimum criteria that employers will have to meet if they are to retain their status as members. For example, hiring at least a certain percentage of disabled people, especially adults living with Cerebral Palsy.**

Flexible working, workplaces, and work practices

The world of hybrid and home working quickly became a reality for a large proportion of the workforce during the last two years. Whilst the pandemic did not provide a silver bullet for facilitating adults with Cerebral Palsy into the workplace, it emphasised that the needs of each adult can be carefully and successfully considered by current and prospective employers.

In her submission to the APPG, Chloe Harri argued her experience of living with Cerebral Palsy meant that: *'There should also be disability leave, so it is easier to take time off for hospital appointments etc and more flexibility around working from home if it makes it easier to manage Cerebral Palsy.'*

Ms. Harri's words were echoed by another adult with Cerebral Palsy, Rebecca Hindson: *'As I am in the shielding category due to asthma diabetes Cerebral Palsy and being 50 my GP has signed me to work from home. This has relieved much of the pressure and means I have more control of my day and is beneficial to my work.'*

Another member of the adult Cerebral Palsy community, Cameron Wood, echoed these sentiments when he spoke about the *'beneficial experience'* that working from home had brought him in his work and studying. He also highlighted how he would be looking for employment roles that offered this flexibility going forward.



Working from home would enable more disabled people to work and to contribute to society."

Rebecca Hindson, adult living with Cerebral Palsy

The lessons of the pandemic must not be quickly forgotten and should be used to inform how we open the workplace for adults with Cerebral Palsy.

The reality for those living with fluctuating conditions, such as Cerebral Palsy, to manage their disability while staying in work must be realised in both employment rights and procedures. This includes introducing the right to request flexible working from the same employer more than once in calendar year, to a maximum of once a month. Employers would also be required provide a written explanation for any decision to reject any request to work flexibly.


There are several procedural changes employers must implement that are beneficial for supporting adults with Cerebral Palsy into work, which include:

- Assessing an applicant's interview process to determine the level of disability leave they are likely to require from their prospective employer.
- Ensuring all job are clearly advertised in an accessible and clear format, putting special consideration on the colour, font and size of text used.
- Ensuring that equal opportunities forms completed as part the application process are only seen by the HR team overseeing the process and not the interview board/panel.
- Organisations should facilitate the creation of disabled staff networks to draw up policies for disabled employees in cooperation with HR. Each network should have a champion at the company board level, especially for adults living with Cerebral Palsy to be able to speak to their specific needs.

Another person with lived experience of Cerebral Palsy underlined the importance of adapting workplaces as more of us returned to in-person working:

'I think there needs to be more awareness around the need for changing places toilets in workplaces [...] [including] how things should be managed and adjusted so that the employee can do the job to the best of their ability.'

Given the radical changes work settings made to deal with COVID-19, many of those giving evidence on their lived experiences to the APPG wondered whether a similar energy can be discovered for making the changes needed to allow them greater access. Changes in the working environment and processes must be employer-led with the direction of travel highlighted by policymakers.

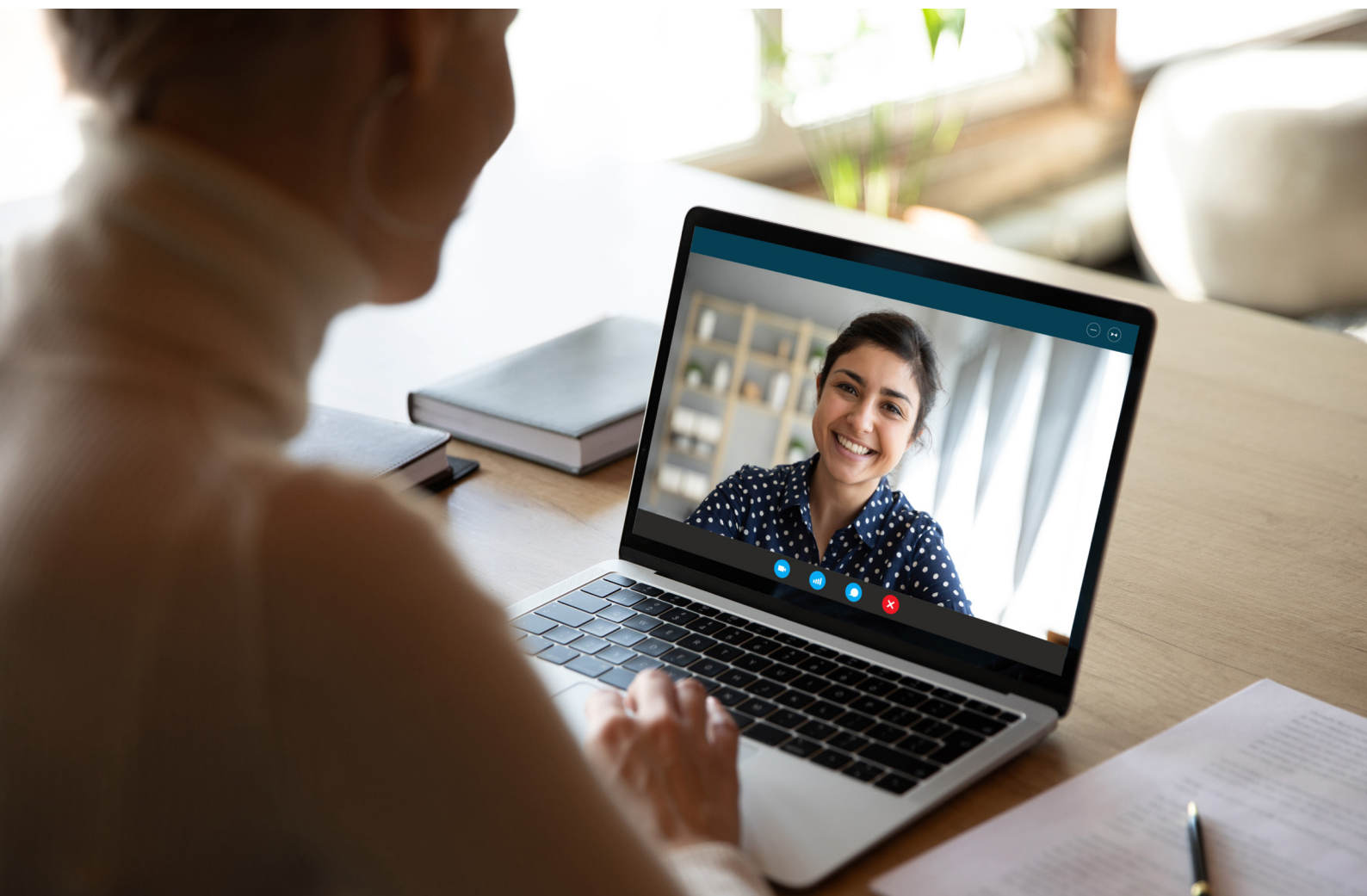


Judith Baron worked as a secondary school teacher for 30 years but was forced to stop teaching because her school was unable to adjust her working pattern to allow for her fluctuating energy levels related to her condition, which she expended doing daily tasks. Removing barriers adults with Cerebral Palsy face in work can only be done with regular conversations, reviews, and adjustments to allow them to remain active participants in the workplace.

Mobility challenges are one the most common workplace barriers encountered so employers cannot ignore the barriers adults with Cerebral Palsy face in travelling to work. Flexible working will not be possible in every role and structural adjustments to a workplace offer limited effect if an employee cannot reach the office. Employers need to discuss mobility requirements with applicants for any role when they apply. These conversations will highlight where the employer should act or bring to the attention of other relevant bodies, such as public transport authorities.

Mobility solutions suitable to the varied requirements of adults living with Cerebral Palsy must be as available as possible in every workplace. This includes providing funding for using private hire vehicles if public transport or car travel are not viable options.

It is the responsibility of employers to make structural adjustments to ensure accessibility for adults with Cerebral Palsy with mobility issues, especially if a lack of access to the employer's place of work is a barrier to working with them. However, Government can support these changes by making changes to the Access to Work scheme, as set out below.



Levelling up Access to Work, information, and support

Changes in the workplace need clear policy and guidance from the Department for Work and Pensions. These mean professionals, such as Job Centre coaches, learning from the lessons of where the system has failed adults living with Cerebral Palsy in providing for their varied needs. More information about support services and organisations should be easily and widely available for people with Cerebral Palsy through central hubs or services.

Any meaningful definition of 'levelling up' must recognise the role of the welfare system to empower groups like adults living with Cerebral Palsy into the workplace.

The Access to Work programme is a key tool for policymakers and a lifeline for the adult Cerebral Palsy community. Claire Duffett outlined how cutbacks in the scope of this vital scheme impacted her entering the second phase of her career. She wrote:

"When I was a student, all equipment I needed from my Disabled Student Allowance assessment was issued to me to keep, not the university. I see no reason why Access to Work shouldn't work the same way."

Ms Duffett's experiences are supported by other cases provided to the APPG by disability organisations, such as Scope, alongside the need to address this issue through reform of the welfare system.

The current 'Shaping future support' Green Paper must improve the employment support offered to adults living with Cerebral Palsy through the welfare system. This includes ensuring that DWP work coaches receive comprehensive training around disability equality and communication skills and being fully informed of the wider support available, especially in relation to employment and training opportunities for adults with Cerebral Palsy.

The APPG urges the Government to use the 'Shaping future support' Green Paper to restore the enabling scope of Access to Work for adults living with Cerebral Palsy. This should include:

- Access to Work meeting the cost of structural adjustments needed by employees.
- Making funding available to employees, especially SMEs, to fund adjustments during an employee with Cerebral Palsy's probation period to support their retention in the business.
- Issuing portable equipment to the service user, not the employer.

Supporting employment and retention in the wake of COVID-19

The last two years has seen a plethora of measures rolled out aimed at supporting retention in the wider labour market. However, the rapidity of responses necessitated by the pandemic inevitably meant that the needs of many groups, including adults with Cerebral Palsy, were not recognised in these.

Analysis from the disability charity, Scope, of the *Understanding Society* dataset showed that disabled employees were more likely to lose their jobs than non-disabled counterparts in the pandemic. Disabled workers, including many members of the adult Cerebral Palsy community, were also more than twice as likely to report poverty income and face problems whilst paying household bills, three times more likely to experience financial difficulty, and four times more likely to experience food poverty.

With the cost of living projected to rise throughout 2022, it is more important than ever that adults living with Cerebral Palsy are afforded every opportunity to find secure, well-paid work. Better retention of disabled employees is needed to address both the employment needs of the adult Cerebral Palsy community and the wider disability employment gap. Every year, for every 100 disabled people who enter the workplace, on average, 118 leave.

To address this, Government should adapt solutions put in place to support the wider labour market during COVID-19. This would include **allowing disabled people over the age of 24 to access the Government's Kickstart Scheme to provide adults with Cerebral Palsy access to valuable work experience as well as high quality support to support their progression in the workplace.**

Interventions such as the Kickstart Scheme were intended to be time-limited and necessitated by the events of the pandemic. However, the scale and effectiveness of interventions in the labour market, like the Coronavirus Job Retention Scheme, demonstrated that targeted support with the necessary resources can be highly effective. Our country can build back better by maximising the participation of adults with Cerebral Palsy to in the world of work.



Afterword by Adult CP Hub and Scope

It is our hope that the All-Party Parliamentary Group on Cerebral Palsy's report on Barriers for Adults with Cerebral Palsy on achieving full life participation through access to healthcare services and progressing at work will help raise awareness and address the unmet needs of a 130,000 strong community of adults living with Cerebral Palsy in the UK.

Informed by a diverse range of adults with Cerebral Palsy, this report uses their voices and experiences to dispel the myth that Cerebral Palsy is a childhood condition. It is not. It is a lifelong condition that deserves and requires the same level of service provision as other comparable neurological conditions.

We welcome the extensive contributions from the medical and researcher community, which gives evidence to the power of collaborative working and the benefits of full stakeholder engagement.

This report highlights that the problems faced by the community are multifaceted and that collaboration between health, social care and employment is essential. This report also serves as evidence that people are unprepared for the secondary effects of ageing with Cerebral Palsy and that there is a general lack of knowledge about the process amongst the community and those supporting them.

We think some of the solutions are simple; take the models and support structures that already exist for other long-term conditions and apply them to the Cerebral Palsy community and address the geographical variation of vital support across the UK.

Adults with Cerebral Palsy must have the option of accessing specialist services from the age of 18 to address the cliff edge moving into adulthood. They also require clear care pathways and the utilising of existing community services by doing away with age-related criteria and therefore leaving GPs empowered to effectively co-ordinate care.

With small steps radical changes can be made.

This report seeks to show how access to healthcare and the world of work are inextricably linked, and that there are many opportunities available to Government to ensure that adults with Cerebral Palsy are not left behind. With the National Disability Strategy, the implementation of the new ICS Framework, the Government's Levelling Up agenda, and the focus on recovering from the pandemic, there has never been a better time to make positive policy change that will improve the lives of adults with Cerebral Palsy.

As we negotiate our way out of the pandemic, we would urge the Government to pay real attention to how changes to the way we have worked have had enormous benefits for many people living with Cerebral Palsy. These changes have been called for by disabled employees, including those with Cerebral Palsy, for many years. They have helped many disabled people manage pain and fatigue caused by an impairment or condition, and reduced anxiety caused by having to navigate inaccessible public transport systems and workplaces.

Addressing and halving the Disability Employment Gap is beneficial to the economy in the region of £50 billion a year and would lead to Exchequer benefits of around £17 billion a year. As well as flexible working, ensuring that programmes such as Access to Work and Disability Confident are fit for purpose will have a positive impact on job retention and help reach the Government's target of closing the Disability Employment Gap.

We urge the Government to use the recommendations in this report to act now to improve the lives of adults with Cerebral Palsy. They are a starting point for addressing the unmet needs and health inequalities of the adult Cerebral Palsy community across the country, and many other disabled people would benefit from positive policy change too.

People living with Cerebral Palsy want and deserve the same life chances as those in wider society. This report shows just how close we are to achieving this, and the Government need to act now.

A list of those who contributed written evidence to the APPG's call for evidence, of which we received 60 pieces in total, is as follows:

- Adult Cerebral Palsy Hub (APPG sponsor)
- ALTHEA Project Advisory Group, University of Nottingham
- The Association of Paediatric Chartered Physiotherapists
- British Society for Surgery in Cerebral Palsy
- Baroness Stephanie Fraser and Cerebral Palsy Scotland
- Contributors from The ETERNAL project – Hannah Harvey and Ruth Bailey
- Queen's University Belfast
- Royal College of Surgeons in Ireland, Dublin
- Scope (APPG sponsor)
- University College London Hospitals NHS Foundation Trust
- Judith Baron
- Sophie Buckley
- Sarah Cooper
- Anthea Dendy, Clinical Physiotherapy Specialist in Neurology
- Claire Duffett
- Margaret Foster
- Rebekah Goulston
- Lizzie Hare
- Rebecca Hindson
- Jay Joshi
- Elizabeth Knowles
- Dr. Grace Lavelle
- Timothy Martin
- Dean O'Shea
- Kirsty Parkinson
- Chris Percival
- Anna Scutt
- Nicola Sheehan
- David Smith
- Dr. Kimberley J Smith, Senior Lecturer in Clinical Health Psychology, University of Surrey
- Dr. Sonali Shah, Centre for Research in Ageing and Rehabilitation, University of Nottingham
- Layla Steadman-Bevan
- Leon Taylor
- Susie Turner, Clinical Specialist Paediatric Physiotherapist, Evelina London Children's Hospital
- Karen Watson
- Cameron Wood
- Bethany Young
- Shahd Zorob

The APPG thanks all those who gave anonymous testimonial of their lived experiences, including through the Cerebral Palsy Adult Advice UK Facebook Group, and members of Scope's Network Cerebral Palsy.

A list of those who gave oral evidence to the fifth and sixth meetings of the APPG is as follows:

- The Rt. Hon. Stephen Timms MP, Chair of the Work and Pensions Select Committee
- The Rt. Hon. Caroline Nokes MP, Chair of the Women and Equalities Select Committee
- Dr. Kirsty Colquhoun, Geriatrician living with Cerebral Palsy
- Dr. Charlie Fairhurst, Consultant in pediatric neurodisability & head of children's neurosciences, Evelina London
- Susan Hourihan, Occupational Therapist
- Emma Livingstone, Founder and Trustee, Adult Cerebral Palsy Hub
- Angela Matthews, Head of Policy and Research, Business Disability Forum
- Louise Rubin, Head of Policy and Campaigns, Scope
- Jacqueline Stephens, Cerebral Palsy Advocate, Entrepreneur and Disability Champion
- Susie Turner, Deputy Clinical Lead Paediatric Physiotherapy at the Evelina London Children's Hospital



All-Party Parliamentary Group on

Cerebral Palsy

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