Response to Scottish Government Consultation on Long Term Conditions Framework

1. **Do you agree that Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work?**

NO

People with cerebral palsy (CP) are split on this question. Cerebral Palsy has never had a condition-specific policy approach. Whilst there are NICE guidelines and standards for children and for adults with CP in England, there are no SIGN guidelines in Scotland. NHS England have just published (May 2025) a new Commissioning Framework for children and young people with cerebral palsy, there are no equivalents in Scotland.

Policy and services supporting people with CP in Scotland have always fallen into more general groups – children with exceptional needs and the CEN network or the Neurological Conditions Framework for adults for example. Despite cerebral palsy being the most common cause of childhood physical disability in the world[1] and the fact that the condition is life-long and will lead to deterioration though secondary ageing and other issues, specialist knowledge of the condition amongst statutory services in Scotland is already minimal and grouped with other long-term conditions. Our community feel that a further grouping of issues could mean people with CP are further disadvantaged.

We understand that there can be similarities in treatment approaches amongst conditions. For example, access to physiotherapy, occupational therapy, speech and language therapy and psychology are sought by many long-term conditions. We also note that many people have multiple long-term conditions and many issues will overlap, so we feel that a diagnosis (or any “label”) in itself should not be the key to unlocking referrals to generic services, and remain concerned that too much focus is put on diagnosis and very little thought and resource is given to the services to support people to live with their condition.

People with CP find that they do not make the referral criteria for such generic rehabilitation services or that if they do get to see a health professional, they do not understand the condition, have no knowledge or experience of CP and therefore are unable to support the person effectively. Cerebral Palsy Scotland are already concerned that the needs of the c.12,000 people in Scotland living with CP are not being met or understood currently. This population is invisible and too often ignored by policy makers and service providers. We would like to see this improved and have little confidence that grouping all long-term conditions together into one policy area will do anything to improve support for people with CP.

Cerebral Palsy Scotland has been unable to find an agreed definition of what counts as a “long-term condition”. It is not clear what conditions may or may not be included or excluded in this policy work and what the rationale for this is. Until this is clear, it is difficult not to conclude that grouping

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[1] https://worldcpday.org/wp-content/uploads/2021/08/CPA-Poster-2.pdf

a number of conditions together is either a cost-cutting exercise, in which case we are incredibly concerned about the detrimental affects for people with CP or else is it a lack of understanding of the detail and the nature of different conditions and lack of capacity to engage with the nuances and issues raised by such conditions.

2. **Are there any improvements in prevention, care or support you have seen in a long term condition you have, or provide care and support for, that would benefit people with other long term conditions?**

People with cerebral palsy (CP) in Scotland have seen very little improvements in care. Improvement projects, such as the development of the adult therapy service at Cerebral Palsy Scotland are funding dependent. Only a handful of adults are able to access funding through self-directed support or private means for ongoing, maintenance treatment in the mistaken belief that support is provided by statutory services. They are not! There are no adult specialist cerebral palsy clinicians in Scotland apart from those working for and trained by Cerebral Palsy Scotland. The Neurological Framework Funding funded a number of projects through Cerebral Palsy Scotland, but once funding ceased the work cannot be maintained. In truth, thanks to the increased costs of employment and fair work commitments, we have had to reduce our operating model and ask staff to take pay cuts to sustain our services. We do not feel like valued delivery partners in policy development or in service delivery.

There have been some successes in Scotland that we can point to, for example the CPIPs programme for children with cerebral palsy. However, this too is funding dependent and the rich data the programme has built up on children living with CP in Scotland and the issues they are facing is not shared or used beyond the programme's specific remit. This work could form a keystone of a wider project to understand how many people in Scotland are living with CP. It could be shared with education and independent living services to ensure better transitions for children with CP as they prepare for adult life, something that is woefully failing as there are no adult services for this population to transition to, leaving them feeling like they are "falling off a cliff". The data could also be used beyond the age of 16 years old to understand what services people with CP are using and where are the gaps. However, to date, once you reach the adulthood the information gathered about your condition goes nowhere.

Between 2020 and 2023 Scottish Government funded Cerebral Palsy Scotland to deliver a flexible support service for adults with CP that combined virtual and in person multi-disciplinary therapy for people with CP across Scotland[2]. The work focussed on ensuring the needs of adults with CP were recognised and understood, but once funding ceased, it was not possible to sustain this level of service without funded referrals.

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[2] https://www.gov.scot/publications/neurological-framework-funding-list-of-organisations-funded/pages/self-management-supported-self-management/

In England there are a number of policy and framework documents specifically for children and adults with CP:

NICE:

https://www.nice.org.uk/guidance/ng62

https://www.nice.org.uk/guidance/qs162

https://www.nice.org.uk/guidance/ng119

https://www.nice.org.uk/guidance/qs191

NHS England:

https://www.england.nhs.uk/long-read/commissioning-framework-for-children-and-young-people-with-cerebral-palsy/

All Party Parliamentary Group (Westminster):

https://upmovement.org.uk/wp-content/uploads/2022/08/Barriers-for-adults-with-Cerebral-Palsy-report-March-2022i.pdf

https://actioncp.org/wp-content/uploads/APPG-on-Cerebral-Palsy-report-Early-Identification-Intervention-and-Pathways-of-Care-2021-2.pdf

https://actioncp.org/wp-content/uploads/EHCP-report-APPG-on-Cerebral-Palsy-October-2021.pdf

https://actioncp.org/wp-content/uploads/The-transition-from-childhood-to-adulthood-report-October-2022-Design-V3.pdf

There are no equivalents involving the statutory sector for any of these in Scotland.

3. **Do you have any thoughts about how areas for condition-specific work should be selected? This means work which is very specific to a health condition or group of health conditions, rather than across conditions.**

The CP community overwhelmingly want Cerebral Palsy Scotland to advocate for condition-specific policy development. They report very low levels of recognition of the life-long issues faced by people with CP, a paucity of clinical research into the condition and the lack of access to services and to professionals who specialise in and understand CP. They feel strongly their needs are not being met currently by statutory services and many frankly just feel ignored and not listened to.

Given the inability to provide a definition of what Scottish Government mean when they talk about "long-term conditions", it is difficult to answer how condition-specific work might be selected. Cerebral Palsy Scotland note that during this year, whilst the funding for the Neurological Framework ended with only £3.185m having been spent compared to the Minister's commitment of a total of £4.5m, no further work or funding has been announced, whilst funding has been provided for ME/Chronic Fatigue, Long Covid and Learning Disabilities, without any framework, consultation or strategic approach. The reasons why these conditions have attracted funding and yet the neurological funding ceased are not clear. Such funding pots also lead to short-term, unsustainably fixes rather than long-term change. Cerebral Palsy Scotland fear that pitting conditions against each other to be recognised is unhelpful.

In order to improve the lives of many people with long-term conditions, Scottish Government should be encouraged to work cross-department. The weighting of funding into acute health services often does not affect many of those living with long-term conditions. For example, many adults with cerebral palsy will never need to see a neurologist, but they do need access to regular physiotherapy, good social care services, accessible housing and support to work. A focus on keeping people living with a life-long condition such as CP well and healthy, connected with their community and out of hospital would be far more beneficial than investing in more hospital-based services.

4. **What would help people with a long term condition find relevant information and services more easily?**

People with cerebral palsy (CP) do not know where to find relevant information and services. They therefore are turning to Cerebral Palsy Scotland to provide the specialist condition-specific information and support that they need. Whilst NHS Inform signposts people with CP to Cerebral Palsy Scotland's website[3] we do not receive any funded referrals to our services for children or for adults from any NHS board or any Health and Social Care Board. This is an unfair and unsustainable position.

In response to consultation on this issue, people with CP are calling for a joined-up approach to support across all sectors and fair funding of non-NHS services including information provision and services.

As a start, each health board and health and social care partnership should have a named contact for people with cerebral palsy, as recommended by the Healthcare Improvement Scotland (2019) General standards for neurological care and support. This should be easily available and accessible by all. People with CP have asked for contact numbers and email addresses, as well as just a named person.

Many adults have to rely on their GPs, but GPs are overwhelmed and there is not enough of them who understand the condition, the treatment options and are therefore able to provide the right care and support. Cerebral Palsy Scotland received funding from the Neurological Framework

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[3] https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/cerebral-palsy/

Funding to build a "CP Link Directory[4]" based on our casework and experience[5]. This was cited by Scottish Government as one of the few "sustainable" projects funded by the Framework, but the reality is, as stated in our final report, even though Cerebral Palsy Scotland urged Scottish Government to consider further work to explore the regional differences in access to services for adults with CP that were illustrated by the Link Directory, the cessation of the seconded contracts for the Regional Co-Ordinators meant that further work never happened and with the lack of further funding, Cerebral Palsy Scotland is unable to prioritise sustaining this work.

5. What would help people to access care and support for long term conditions more easily?

Most importantly, people with cerebral palsy require health and social care professionals to understand the lifelong challenges of living with CP.

Scottish Government should develop its own version of the NICE Guidelines and Standards for adults and children with cerebral palsy and consider what a Scottish Commissioning Framework would look like. All health boards and HSCPs should be required to implement these as a minimum standard, and practitioners and clinicians at a local level must be fully aware of their responsibility for prompt referral to expert multi-disciplinary teams at all life-stages for people with CP. All care pathways should include agreed and audited quality standards.

For infants and children with CP there is compelling evidence about the vital importance of early identification and intervention for infants with or at risk of CP and also about the current gaps in joined up care pathways experienced by many families. These families require more support as they navigate the diagnostic, referral, and care process, to empower them to access the best care for their child at what is a deeply distressing time for parents. Specific recommendations for improvement include:

- Support the CPIPs programme and develop a standardised national surveillance programme for preterm babies and infants who are at high-risk of diagnosis of cerebral palsy.
- Fund and ringfence streamlined pathways of care for children at risk of neurodisability that puts the needs of children and families at the heart of all decision-making. Funding must extend to service provision in third sector providers such as Cerebral Palsy Scotland.
- Improvements in transition planning for children looking to leave school and education are essential.

For adults with CP:

Adults living with CP 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

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[4] https://cerebralpalsyscotland.org.uk/wp-content/uploads/2024/11/CP-Link-Directory-Final-Report-April-2024-revised-November-2024.pdf

[5] Supported self-management and preventative care - Neurological Framework Funding: list of organisations funded - gov.scot

support to ensure they can live a full life. There is a common misconception that CP 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 16 years of life as services are overwhelmingly skewed towards early childhood.

Along with other UK organisations campaigning for better services for adults with CP, Cerebral Palsy Scotland are calling for the following improvements:

- Adults with CP should be guaranteed access to annual medical reviews to better assess their evolving health and care needs.
- Scottish Government should invest in collecting data on adults with CP so they are more visible to service providers.
- Generic providers of health and social care services should be required to have completed training in the management of CP before they are able to assess treatment and support options for this population.
- Ringfencing funding should be found for NHS boards and HSCPs to develop specialist CP clinics and services, or else funding should be provided to third sector and private providers of such services if the statutory sector cannot step up.
- Families should not be left to fill in the gaps in support (for example with transport for their adult child) or be forced to choose between giving up their own employment to care for their adult child.

6. How could the sharing of health information/data between medical professionals be improved?

A central point of contact in each area could facilitate the sharing of information and data between professionals. We would advocated that for the cerebral palsy population this cannot be limited to only sharing between “medical professionals”. Cerebral Palsy Scotland would like to see better information and data sharing between all services: primary and secondary healthcare, social care and education and also third sector if applicable.

Personal relationships with professionals were identified by our population as being important to ensure professionals had the right information/data. Some people were advocating for more training on cerebral palsy for commissioners of services, particularly for those responsible for transition planning and GPs, but others highlighted the turnover of personnel and how knowledge gaps were not filled by new people and so they felt they had to start all over again. Others felt that a “culture change” was required as their experience was of professionals “not wanting to know” because they didn’t know what they could do and so therefore the incentive was just to get the person away from their service so it wasn’t their problem. Many felt this was because professionals did not understand the condition. It was noted that other conditions have specialists at different levels, e.g. consultants and nurses for diabetes, epilepsy, Multiple Sclerosis or Parkinson’s Disease.

Some of these conditions (MS and PD) have a similar prevalence to cerebral palsy and yet there are no specialist CP clinics, outwith those provided by Cerebral Palsy Scotland.

7. What services outside of medical care do you think are helpful in managing long term condition(s)? You may wish to comment on how these services prevent condition(s) from getting worse.

It is not possible to "prevent" cerebral palsy (CP) and whilst it is classed as a "non-progressive" neurological condition because the damage to the brain will not change, if a person does not have access to the right therapy and support to keep well then their ability to lead a full life will be curtailed.

It is extremely important for a person with CP at all stages in life to stay as fit and as active as possible. However, there are far too many barriers to enabling people to do just that. Self-management support is not enough. Many people know what they have to do to stay well but they cannot access what they need. This will include:

- Access to specialist annual reviews with a clinical professional who is experienced in the lifelong management of cerebral palsy to assess their evolving health and care needs.
- Access to specialist therapy (physiotherapy, occupational therapy, speech and language therapy, wheelchair services, podiatry, psychology etc.) to address the needs identified in any specialist annual review before they become embedded and the person loses function and ability to remain as independent and as well as possible.
- Access to sports and leisure facilities, including accessible swimming pools and gyms
- Chair and foot care (which is now outside the NHS provision but remains vital to this population to staying well).
- Access to good social care support so that people can lead an independent life and take up employment opportunities.
- Funding for organisations such as Cerebral Palsy Scotland who provide opportunities for social events and peer to peer support.

Such services will never be a "one size fits all". People with CP therefore need to be able to choose what services best suit their needs and be supported to participate in their local communities in order to stay well.

8. What barriers, if any, do you think people face accessing these (non-medical) services?

The main barrier identified by people with cerebral palsy CP was funding. Either such services are expensive and people do not have the resources to self-fund or there is no way of accessing funding. (SDS will not stretch to cover this as it is tightly focussed on social care). Many people with CP are experiencing financial hardship and therefore cannot contemplate paying for gym fees or additional services.

Other barriers identified were a lack of knowledge, both of what could be available and beneficial for people with CP, but also the knowledge of those providing such facilities, e.g. gym staff and swimming pool attendants, some of whom actively discourage people with CP from participating.

There are also other barriers like geographical location and travel costs to get to facilities. Many so-called "accessible" facilities do not have track hoists or suitable changing places. Often they are only available at certain times of the day or on certain days of the week and so people are unable to access them because of this.

People feel it's a lottery as to whether there is awareness of what is available and whether facilities or services are affordable and truly accessible.

Cerebral Palsy Scotland have worked with adults and families to access local community assets. However, such 1:2:1 input is extremely time-consuming and staff resource heavy.

9. **What should we know about the challenges of managing one or more long term conditions?**

Cerebral Palsy Scotland asked our community this question and this is what they came back and wanted us to tell Scottish Government:

"No two days are the same and some things may take longer than others to get to the same or similar outcome"

"One condition being bad can trigger them all to be bad. Wish people understood this"

"That sorting out one issue can have an impact on another and managing multiple conditions is complex and often challenging to do. Look at everything collectively"

"Each person needs a unique health plan and support co-ordinating the various professionals involved and how to manage that in daily life"

"It's really difficult, because they only know how to help with that one condition, and not the others, even although they are enmeshed"

"There are more appointments, more tests, the scoliosis can mean higher risk of choking and aspirating food. Prone to chest infection. Non-verbal, so cannot tell you if something is wrong"

"How difficult it is to get professionals on the same page. Often health care providers treat the one condition and do not understand any other conditions you may have. This makes it challenging to access the right medication, juggle appointments and have whole person approach"

"The need for effective communication and coordination across services, the ignorance around the effect of age on the long-term condition, the need to educate and support those who love and care for the person with the condition"

"It can be tiresome. Sometimes new conditions can come out of nowhere"

"Managing other health conditions is hard your mind needs to be more aware and your body"

"That they all affect each other so cannot be taken in isolation"

"I am not a total of the parts involved in my health struggles, I am a unique whole person and all health issues should be managed on the context of a holistic approach. Eg I have bowel and bladder issues as well as CP, I also have a Baclofen pump which requires monitoring. Given the complex nature of my health and physical needs a lead practitioner should take responsibility of coordinating and reviewing with other health professionals. It has taken years to get things sorted and I nearly died in the process all because surgical staff had no knowledge of my condition. I was treated as a bowel, then a bladder because they could not easily fix me and send me on my way. It wasn't until neurology took the lead that things started to improve. Generally, this is the case, medical professionals treat us the same as someone who doesn't have a disability and this is not always appropriate in a health setting"

"That doctors understand the cerebral palsy and what other conditions that could exist with them"

10. What would strengthen good communication and relationships between professionals who provide care and support and people with long-term condition(s)?

For some people (adults in particular) with cerebral palsy this is an academic question as they don't feel they have access to professionals who provide care and support them. For those that do, they overwhelmingly want:

professionals to listen to them and to their families

for professionals to have a better knowledge of cerebral palsy

to have a single point of contact who can co-ordinate care and support.

One adult commented that they would rather have someone with knowledge of CP caring for them *"instead of the horrendous system at the moment where they think it's appropriate to send anyone in as long as the hours in the care package are met. This is not care. This does not meet the needs of the cared for person."*

Three in four people with CP experience pain and a particular worry for the one in four people with cerebral palsy who are unable to talk is that they unable to communicate the pain and discomfort they are suffering.

11. What digital tools or resources provide support to people with long term conditions?

There are a many digital resources available for children and adults with cerebral palsy, the following for example were a few highlighted by people with CP:

- PAMIS digital passport
- Speaking software such as Trackball or Dragon NaturallySpeaking

- www.cptoys.org

Other resources that people felt were useful included mindfulness apps, apps which can turn lights on and off or Alexa/Google Chrome devices around the home and digital tools that are able to read documents aloud.

However, people expressed frustration at having little knowledge about what might be available that could help them and also concerns around the cost of supporting some tech resources. Cerebral Palsy Scotland source many digital tools from Inclusive Technology: https://www.inclusive.com/

12. What new digital tools or resources do you think are needed to support people with long term conditions?

There is an exciting role for digital tools and resources but they should not be seen as an alternative to quality face to face provision and support services. We would urge Scottish Government to consider what is already available or has already been developed rather than developing digital tools from scratch. (The sorry state of the proposed NHS Scotland app is an example of where this has seen many promises and no doubt much resource committed with no discernible outcome, whereas if NHS Scotland had partnered with NHS England, everyone in Scotland would now have access to their health records on an app).

13. How do you think long term conditions can be detected earlier more easily?

Cerebral Palsy is an umbrella condition that affects everyone differently and to a greater or lesser extent. It will always affect movement and physical development. As well as affecting movement, CP can affect other areas of function:

- 1 in 3 are unable to walk
- 1 in 4 are unable to talk and will use alternative methods of communication
- 3 in 4 experience pain
- 1 in 4 has epilepsy
- 1 in 2 has a learning disability
- 1 in 4 has bladder control issues
- 1 in 5 has a sleep disorder
- 1 in 5 has saliva control problems

There is no cure for cerebral palsy and although the damage to the brain does not worsen, the effects of the condition become more debilitating with age. As a person with CP grows, they can develop secondary muscular skeletal problems, such as increased tightness in muscles and joints and dislocations. This can change a person's physical abilities over time. People can also experience increased issues with pain and fatigue. Often these symptoms can mask other issues that prevent people with cerebral palsy gaining access to services and lead to lives being shortened due to lack of access to care for a condition unrelated to their cerebral palsy.

As cerebral palsy is caused by damage to the infant brain, either pre, during or shortly after birth then most people with cerebral palsy have lived with the condition all their lives, so they are not searching for a diagnosis, although some people with cerebral palsy can be 'missed' in the early days and not receive a formal diagnosis until much later in life. Cerebral palsy is an umbrella term that covers many different presentations and sometimes this can confuse the person, carers and professionals.

The NHS take a "wait and see" approach to children at risk of developing a neurodisability or cerebral palsy. Research shows that early identification is key to improving the outcomes of these children. Cerebral Palsy Scotland is calling for the following to be developed and implemented:

- A frontline workforce who are knowledgeable about CP across health, education and social care
- Equitable and swift access to centres of excellence in CP for specialist therapeutic, multi-disciplinary input and provision of specialist equipment
- Collaboration across sectors (including third sector organisations such as Cerebral Palsy Scotland) to support children and their families and boost availability of specialist support and intervention
- Support for parents and carers during the key early years to build essential pathways for brain development and general future wellbeing of the child

14. What barriers do people face making healthy decisions in preventing or slowing the progress of long term condition(s)?

Adult services for people with cerebral palsy (CP) should, in theory, adhere to the standards set out in Healthcare Improvement Scotland's General Standards for Neurological Care and Support. In practice care and support often does not meet these standards.

There is a lack of a knowledge of cerebral palsy within the health and care workforce in Scotland, particularly in adult services. This means there is very little access to specialist therapeutic support to enable people with CP to stay well and healthy throughout life.

Children with CP in Scotland are seen through specialist children's services in their local communities and some will have regular reviews with consultant paediatricians. There are no specialist statutory services for adults with CP in Scotland, a situation recognised throughout the UK.

Within statutory services, CP is seen as a static condition and so people are not regularly assessed and problems are often left until they become acute due to lack of staff knowledge of the condition, the changing needs of people with cerebral palsy and the effects of, for example, secondary ageing. However, people must be supported to be able to reach their full potential. Often people with cerebral palsy can become so accustomed to their condition that they do not see the potential for change. This is then reinforced by professionals who also view the condition as unchanging and too often give the response that nothing can be done. People with cerebral palsy should be offered a regular review and assessment of their needs

Many people with CP are able to lead long and fulfilled lives, however, others require access to a range of services. Many adults have social care needs and rely on carers and PAs (personal assistants) to live their lives. Most adults access this support through general adult disability services. There is limited or no access to specialist input. Staying well, with regular access to specialist multidisciplinary therapy, is key to maintaining good health for people with cerebral palsy.

The common factor constraining the lives of adults living with CP is the geographic variations in vital support across Scotland, as illustrated through Cerebral Palsy Scotland's work on the CP Link Directory. Life expectancy for adults living with Cerebral Palsy is strongly associated with motor function and feeding skills, but most adults with mild to moderate CP can expect to live as long as those who do not have CP. Sadly, the transition into adolescence and adulthood is often accompanied by a decline in physical function, with 20-50% of people with CP experiencing deterioration in walking function between 20 and 40 years of age.

Preventing the slow decline for people with CP can only be achieved when there is collaboration between all services, for example: the NHS, social care, third sector and other support organisations including employers and colleges. Cerebral Palsy Scotland feel that this will not be addressed until we have better data and therefore better visibility of people living with CP in Scotland, which is why we have called on Scottish Government to support the development of a Cerebral Palsy Register. Analysis from the Northern Ireland Cerebral Palsy Register has shown that the prevalence of CP in adults is comparable to that of

Multiple Sclerosis or Parkinson’s Disease. However, health and care services for adults with CP in Scotland fall short of what is needed in relative terms.

15. Is there anything currently working well within your community to prevent or slow progression of long term conditions?

The NICE guidelines for adults with cerebral palsy recommend regular specialist reviews for adults with CP. Cerebral Palsy Scotland have been offering specialist reviews since 2019 (subject to funding): https://cerebralpalsyscotland.org.uk/how-we-help/for-adults-individual-therapy/specialist-review/ We would like to see this service put on a more sustainable footing and work with statutory partners to expand this service across Scotland.

We would also recommend Scottish Government look at the multi-disciplinary Adult Cerebral Palsy service at the University College London Hospitals’ (UCLH). This service provides:

- 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, (for example a 3-session modules in coping with fatigue, pain, social communication, and transitions
- 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 specialist physiotherapist, available three days a week; Occupational Therapists available two days a week; a day a week of Speech and Therapy, Psychology support; and the required administrative support.

16. How can the Scottish Government involve communities in preventing or slowing the progress of long term conditions?

Cerebral Palsy Scotland continues to be disheartened at the lack of engagement between our condition-specific specialist services for children and adults with cerebral palsy and the more generic (out of necessity) statutory provision. We believe our experience and expertise, as well our relationships with the cerebral palsy community in Scotland, could be of great benefit to improving services for this population. However, despite warm words, we receive no funded referrals from local community services, and in some cases our input and supporting evidence are actively discouraged.

An organisation, we want to see local community statutory services improving and would adapt our service offer to support this. Often our role is to support people with CP and their families whose relationship with statutory providers has broken down to re-engage.

We have developed a successful outreach model across areas of Scotland from Aberdeenshire, the Western Isles, Argyll and Bute and the Lothians that has proved successful in engaging local communities and organisations in these areas in improving care for people with CP. However, despite working closely with local NHS teams who manage referrals to this service and feedback from local staff confirming the value of our input, all of this work has to funded by Cerebral Palsy Scotland.

As an organisation, we are invited to meetings and networking events, to lecture students and train carers. We are expected to turn up and contribute for free and it is assumed that we will just continue to provide our services and pick up the pieces when the statutory sector fails people. This does not feel like partnership working to us.

17. **Are there additional important considerations for people with long term conditions? For example people who; live in deprived areas and rural and/or island areas, have protected characteristics e.g. race, disability, who are in inclusion health groups e.g. homelessness, or who experience stigma due to perceptions of their long term condition e.g. people with dementia?**

People with cerebral palsy (CP) are discriminated against because of their condition and the low expectations people have because of their condition.

For example, people have difficulties in accessing dental treatment because they are unable to sit in the dentists' chair, or they are denied access to smear tests or mammograms, again because the clinics are not accessible to them.

In hospital and residential settings people report nurses and care workers who have not been properly trained in caring for people with CP assuming things that are incorrect and therefore not moving and handling correctly, causing pain and distress.

People also report that their needs are not fully assessed by service providers. For example, one person reported that their deafness was not acknowledge and they have never been asked if they would like an interpreter because their support worker is with them, however, their support worker may not have signing experience and may not be the appropriate person to interpret consultation appointments.

Whilst one in two people with CP also have a learning disability, it is extremely frustrating for people with CP that it is assumed that everyone with the condition has a learning disability. As one person reported "*I have to work harder to prove myself*".

18. Given that racism and discrimination are key drivers of inequalities, what specific actions are necessary to address racism and discrimination in healthcare?

The discrimination experienced by our population is due to their condition, as outlined in the previous answer.

19. Is there anything else you would like to raise that was not covered elsewhere in the consultation paper?

Cerebral Palsy Scotland is very concerned that the Scottish Government is not listening to the communities it claims to be consulting. Based on discussions with government officials and with sector colleagues, we believe that the Scottish Government intends to progress with a Long-Term Conditions Framework irrespective of the responses to this consultation.

In order to provide Scottish Government with the most comprehensive views of the cerebral palsy community, Cerebral Palsy Scotland consulted widely before submitting this response. Our community were keen to engage. They, like us, want to see change and improvement. Responding has therefore not been a quick, an easy or a no-cost exercise for us. However, we do not feel that there is real opportunity for us to meaningfully shape the outcome. We even wonder who will read all of our responses and if anyone will respond to any of the issues we've highlighted.

Along with other third sector organisations, we are concerned that there has been no direct engagement with us, or with people with CP, about the introduction of a long-term conditions framework and we would contrast this with the detailed engagement and preparatory work that was undertaken by Scottish Government in the run up to the development of the Neurological Framework for Action 2020-2025.

We would like to support Scottish Government and local services to improve services and support for people with cerebral palsy in Scotland. That is the very essence of our charity's mission. However, at this point both ourselves and our community are far from convinced that another framework, another strategy, especially one that takes no account of the issues faced by people with CP, will do anything to improve services that many on the ground are already seeing being cut at this very moment.

Further information about your organisation's response

Response to Scottish Government Consultation on Long Term Conditions Framework

Organisations may use this space to provide additional context for their response. This could be information about, for example:

- **any research your organisation undertook to inform the response**
- **any engagement with your members or audience undertaken to inform the response**

Cerebral Palsy Scotland has 30 years of experience of the management and treatment of people with cerebral palsy in Scotland. We employ clinical specialist physiotherapists, occupational therapists and speech and language therapists who are all trained in the Bobath concept and have experience in the both statutory and third sector provision, within Scotland and internationally. We also work with a consultant psychologist to provide condition-specific mental health and wellbeing support and to enable a psychologically informed approach to all our services.

Cerebral Palsy Scotland is the only charity dedicated to supporting people of any age living with cerebral palsy in Scotland. As we have developed, we ensure our work is guided by what is best and what is needed by people with cerebral palsy and their families in Scotland. We aim to improve the lives of children and adults with cerebral palsy through specialist therapy; our groups reduce isolation, bringing people with cerebral palsy and their families together; our support service offers a listening ear and advice. We share our knowledge and skills through courses, conferences and working collaboratively. We raise awareness and we campaign for life-long access to knowledgeable, compassionate services and support.

Every year we see around 250 children and adults with CP and their families for direct therapeutic support. Most of our funding comes from our own fundraising. We receive no funded referrals from NHS boards, HSCPs or Local Authorities.

We drew on our clinical expertise and experience to inform our consultation response. We also drew on previous projects and research that can be found here: https://cerebralpalsyscotland.org.uk/key-documents/

To guide our response we conducted a survey of our community specifically tailored for this consultation. The survey was sent to all our service users, to their families and carers, across Scotland.

Cerebral Palsy Scotland works collaboratively with organisations involved in supporting children and adults with CP across the UK. We were members of the All-Party Parliamentary Group in Westminster for cerebral palsy and are members of the Cross-Party Group for Disability in the Scottish Parliament. We have drawn on the work of these groups to inform our response as well.

We are also members of the Health and Social Care Alliance of Scotland and the Neurological Alliance of Scotland and have contributed to engagement events run by both organisations on the consultation.

Our CEO, Stephanie Fraser, was Chair of the National Advisory Committee for Neurological Conditions until 31st March 2025.