

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC80 : Ymateb gan: Cerebral Palsy Cymru | Response from: Cerebral Palsy Cymru



Russell George MS
Chair
Health and Social Care Committee
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

11 August 2023

Dear Russell

Inquiry into supporting people with chronic conditions

Further to your letter of 13 July, I am pleased to write in my capacity as Centre Director of Cerebral Palsy Cymru with written evidence towards your inquiry into supporting people with chronic conditions.

Context/ About Cerebral Palsy Cymru

Cerebral Palsy Cymru (CPC) was established in 1992 to improve the quality of life of children in Wales living with cerebral palsy. It is the most common form of physical disability in children worldwide and in Wales there are approximately 1,800 children / 6,000 adults with cerebral palsy, with a baby being born with the condition every 5 days.

CPC comprises expert physiotherapists, occupational therapists and speech and language therapists who are at the forefront of clinical practice in cerebral palsy and who work in a unique, trans-disciplinary way. We are all highly trained and experienced in our individual disciplines with extensive, advanced level post graduate training and expertise in the treatment of cerebral palsy. The therapy provided is individualised and bespoke for every child, as cerebral palsy is a significant and hugely complex condition, where no two children present the same. Impact is measured using specific measurable therapy goals and the Goal Attainment Scaling (GAS) measure.

The charity also co-leads the development of the Cerebral Palsy Register for Wales to collate data to help facilitate better planning of services, housing etc, raise standards of care and ultimately reduce the incidence of cerebral palsy. This work will result in Wales being the first nation in Great Britain to have a Cerebral Palsy Register. Please see Appendix II.

In addition, we provide training programmes to upskill therapists in Wales and, increasingly, across the world. CPC also presents the impact of its work and the results



of audit studies to international conferences¹, contributing to Wales' growing reputation as a world leader in the treatment and management of cerebral palsy.

NHS and social care services - the readiness of local NHS and social care services to treat people within the community

The availability and quality of services for families living with cerebral palsy across Wales could be described as a 'postcode lottery'. Most commonly, there is currently very little, if any, specialist support available other than what we provide. We are continuously reminded that the provision of therapy input locally for families is hugely variable and inequitable, and parents often report feeling 'left' after being discharged from neonatal units. Where support is available, it is usually from general clinicians, rather than a practitioner with specialist expertise in the treatment of cerebral palsy. One parent reported: *"There is a feeling of worthlessness, as the family want to see the specialist, rather than a general paediatrician."* This is explored further in the following report: [Complexity and challenge in paediatrics: a roadmap for supporting clinical staff and families | Archives of Disease in Childhood \(bmj.com\)](#)

Cerebral Palsy Cymru conducted family focus groups in October 2021, from which a common theme was the lack of information/ signposting to support services for children and families living with cerebral palsy. This suggests the need for a care co-ordinator as a central point of information and communication and to facilitate parent involvement in the decision-making process. Because of the severity and complexity of cerebral palsy, there are a number of services/ practitioners involved in the care and treatment of a child, including NHS physiotherapists; physiotherapy technicians; occupational therapists and technicians; speech and language therapists and technicians and other professionals. Parents reported a lack of information and control over referrals being made – *"The referral process from hospital to community has felt out of control. Physio has become a co-ordinator, needing to check referrals have been made to other services. There are no letters to confirm that we are on waiting lists. I would like someone to speak to I feel lack of control over that".* Another parent commented: *"Control has been taken from us with decisions being made in the background. It would be good to have a care co-ordinator - we don't feel that different services talk regularly to each other.* Another parent added: *"We received no early referral to Cerebral Palsy Cymru but found it on Google. The contact we have had from Cerebral Palsy Cymru has given us lots of information about what to do now and about the future. Without them feel we would be at the whims of Google. We need amalgamation of someone to co-ordinate and give you information to avoid you going down a path you should not go down".*

Cerebral Palsy Cymru, through its family support service, connects and signposts families to charities, such as SCOPE, Cerebra, Disability Advice Project, Disability Sports Wales, Swimkids, Pedal Power (disabled cycling), and Sealegs2 (disabled sailing). However, there is a need for NHS and social care services to direct families to the resources available for supporting parents through the voluntary sector to help them manage their child's treatment and care, particularly in relation to treatment and early

¹ Examples include the International Alliance of Academies of Childhood Disability, the European Academy of Childhood Disability, the Association of Paediatric Chartered Physiotherapists, Indian Academy of Childhood Disability.



advice services. This needs to be addressed through improved awareness and co-ordinated access to information.

Support available for self-management e.g. mental health support

Having a child with cerebral palsy places enormous pressure on family life, significantly affecting the mental health of parents and siblings. Cerebral Palsy Cymru provides a Family Support Service, which gives parents and carers practical and emotional support as well as signposting to other health and social care services in the public and third sectors as mentioned above. This Family Support Programme, thanks to a successful application to the National Lottery Community Fund, will - from autumn 2023 - be augmented by a clinical psychologist who will help parents manage this traumatic period in their lives, better enabling them to care for their children. The child parent relationship has a strong influence on a child's progress and outcomes. This will influence both the child and parents' future as well as help protect the parent-to-parent relationships. There is a higher level of family break up in families with a child with a disability. Helping prevent this will reduce the cost this places on families and society. It also reduces the additional Adverse Childhood Experience (ACE) this creates for the child.

This support is unique, is not available through local teams and is not replicated by any other organisation in Wales. Whereas other charities and services offer advice to parents or carers of disabled children around practical issues such as benefits entitlement, none offer this on an individual 1-to-1 and face-to-face basis, and none is specific to cerebral palsy, or importantly, offered from birth (rather it is more general advice around disability). Other services will also often require the child to already have a diagnosis, or be on diagnostic pathway, so some of the families we currently see would be excluded. There is also a uniqueness, not seen elsewhere, in how closely our Family Support Coordinator works with our Strategic Lead for Early Intervention in assessing the child's and family's needs. This close working relationship ensures holistic care for the family right from the start. Our early intervention programme, *Better Start, Better Future* addresses and supports each family's personal and unique challenges. A number of parents during the last year have mentioned being diagnosed with post-traumatic stress disorder (PTSD). While looking at mental health service provision for families living with cerebral palsy in Wales, we can see that the situation is similar to that described in a recent research paper commissioned by Cerebral Palsy Scotland (independent charity). The CP Community in Scotland agreed that 'understanding the psychological impact of living with cerebral palsy was a current support gap and priority.' The research established that 'there were no clearly defined specialist mental health services for individuals with a diagnosis of cerebral palsy'.

It is expected that parents of children with cerebral palsy, predominately the mother, become healthcare providers as well as parents, 24 hours a day, 7 days a week. The health of parents is important, both in terms of caring for their child but also in their own right to health and well-being. Most healthcare services focus on individual patients and not the whole family, therefore ignoring the needs of parents.

Some research has been undertaken into both the physical and psychological pressure of having a child with a chronic or life-limiting condition. This can include a higher incidence of anxiety, depression, serious mental illness (schizophrenia and bipolar disorder, back pain, obesity, hypertension, cardiovascular disease and Type 2 diabetes



mellitus). There is also evidence of an increased risk of mortality among mothers whose infant has died or has a significant congenital anomaly. The full article can be found here: <https://adc.bmj.com/content/106/10/987>. More work needs to be done to understand and to make support available through NHS and social care services to mitigate the physical and mental health outcomes of individuals caring for children with chronic conditions.

Young people with cerebral palsy often feel isolated and stigmatised as a result of their physical disabilities, which impacts on their mental health. There is little support available to support and tackle this. Cerebral Palsy Cymru has established a Cerebral Palsy Youth Voice Wales group with a number of young people who have cerebral palsy, to reduce isolation, give young people with lived experience an opportunity and platform to have their own voice, to make friendships, to share common issues such as discrimination and also to feedback into our service design and development. One of the recent participants expressed the importance of having a specific group as most commonly *"all disabilities are grouped together and once size does not fit all"*.

There therefore needs to be more emotional and mental health support available, both for individuals who have cerebral palsy and for families caring for those living with the condition.

The ability of NHS/ social care providers to respond to individuals with multimorbidity

In terms of therapy provision, our gap analysis shows clearly that we are the only service in Wales working in a transdisciplinary way, i.e., therapists able to move beyond the traditional boundary of their own discipline and, work together, addressing areas normally the concern of the other two therapy disciplines. Our therapists also work in a multidisciplinary way, discussing and treating a child together. Most NHS and private physiotherapists, speech & language therapists and occupational therapists see children independently of each other. Transdisciplinary working provides a more seamless intervention and a greater understanding of how all elements of the child's condition interrelate. This is important in providing intervention with the greatest impact.

Impact of pandemic on quality of care

Our experience supports the view that COVID-19 has negatively impacted several areas of functioning - including mental health, and human rights of people with disabilities and their families/ caregivers in Wales. The following article examines the major disruptions in service provision, participation, and overall well-being of children and young people with disabilities and their families worldwide: <https://iaacd.net/2023/05/02/covid-19-data-coordination/>

However, there have also been positive aspects during the pandemic, such as with remote health services/ training. In our own experience, we are able to offer virtual appointments and are able to invite other professionals involved in the child's care to join appointments/ consultations virtually. Virtual appointments are also beneficial for those who cannot afford to travel or whose child may be too ill to travel. However, it is worth noting that virtual service provision cannot replace assessments, support and/or interventions requiring in-person interactions and/or physical contact. 46 out of 1060 appointments (4%) were virtual in 22/23, compared to none pre-pandemic.



Impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing

All of CPC's services are currently provided free of charge to every family. This is a fundamental premise of the charity as families who have a child who has cerebral palsy are likely to be socially and economically disadvantaged². This is supported by a growing body of evidence and is reflected to some extent by our own referrals, with the Cwm Taf Morgannwg University Health Board accounting for 25% of all referrals to our *Better Start, Better Future* early intervention service since 2016 (covering the Merthyr Tydfil, Rhondda Cynon Taf and Bridgend Local Authority areas which have some of the most deprived areas of Wales according to the Welsh Index of Multiple Deprivation). Consequently, many of our families are reporting increased pressures on their health and wellbeing as a result of the rising cost of living. Please find below a link to Disability Wales' report into the impact of the cost-of-living crisis on Disabled People in Wales, which supports our own findings:

<https://www.disabilitywales.org/report-launch-barely-surviving-the-impact-of-the-cost-of-living-crisis-on-disabled-people-in-wales/>.

Action to improve prevention/ early intervention

Early intervention is critical for children with cerebral palsy. For the last 8 years, CPC's main focus has been its early intervention service, *Better Start, Better Future*, which gives babies in Wales who have, or are suspected of having, cerebral palsy the best possible start in life. Early intervention maximises the opportunity to establish neurological connections in a way that is only possible up to 2 years post term age. This optimises the possibility of developing skills and function, which decreases the level of disability and dependence, including reducing aspects such as contracture and deformity, and reduces the need for expensive, rescue interventions such as surgery. *Better Start, Better Future* improves a child's sensori-motor development, increasing their functional abilities and thereby enhancing their ability to participate in life situations and their independence as adults, with less need for state support. Early intervention also significantly reduces the economic burden of cerebral palsy on individuals, families,

² Solaski, Majnemer, Oskoui (2014), *Contribution of socio-economic status on the prevalence of cerebral palsy: a systematic search and review*. Published in *Developmental Medicine & Child Neurology* 56(11).



society and the NHS³. CPC's early intervention programme has an international reputation for excellence, with requests to visit the Centre from as far afield as Brazil, Belgium, Spain and Singapore. CPC was invited by the European Academy of Childhood Disability, Early Intervention Special Interest Group to present our programme at an international conference of colleagues in the field in Slovenia earlier this year.

Some of the benefits of early intervention are illustrated in Evan and Noah's stories:

Evan

"Our son Evan was born at 26 weeks and unfortunately at 72 hours of life had medical complications relating to the blood supply to his brain which sadly are not uncommon in extremely preterm babies. This resulted in a weakness in Evan's left side of his body" explains Evan's mum, Lauren. "After finding out about Cerebral Palsy Cymru, I self-referred Evan and after an initial consultation, he is now regularly attending their children's centre for specialist early intervention occupational and physiotherapy. The progress of his left-hand side is incredible. Some examples are that he is now able to put both hands on his bottle, not just his right hand. Following the recent Ei SMART early intervention infant course, he is now able to put both feet on his pram bar. He can now also reach out and feel our faces with his left hand too.

"The enhancements we've seen in his left-hand side are down to the extremely valuable early intervention techniques we've learned and which we work hard to put into practice at home. There was a time when we couldn't think too much about his future, what he was or wasn't going to be able to do but we are now very optimistic for his future and that is a wonderful feeling."

Noah

"Being involved with Better Start, Better Future has made such an incredible difference to our life. There was a time when I wondered if Noah would move normally at all and now to look at him, that thought is almost unbelievable. Every time he cruises along the furniture or crawls across the floor, I am reminded of how much time and effort the team

³ Cerebral palsy is a significant economic burden on a country. Work in Denmark has shown a lifetime cost of 800,000-860,000 Euros (Kruse M, Michelsen SI, Flachs EM, Brønnum-Hansen H, Madsen M, Uldall P. Lifetime costs of cerebral palsy. *Dev Med Child Neurol.* 2009 Aug;51(8):622-8. doi: 10.1111/j.1469-8749.2008.03190.x. Epub 2009 Mar 24. PMID: 19416329) and in the USA \$921,000 (Centers for Disease Control and Prevention (CDC): *Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment--United States, 2003.* *MMWR Morb Mortal Wkly Rep.* 2004 Jan 30;53(3):57-9. PMID: 14749614.) In Northern Ireland research showed that cases of CP represented 0.3% of the population aged 0 to 24 years but accounted for 1.6% of hospital admissions and 1.6% of outpatient appointments. They had higher rates of elective admissions and multi-day hospital stays than the general population. Respiratory conditions were the most common reason for emergency admissions. Those with most severe CP were 10 times more likely to be admitted, and four times more likely to attend outpatients, than those with mild CP. We do not know the costs or rates for Wales but we know it is significant and that increased severity of CP increases the economic burden (Tonmukayakul, Sophy T.F. Shih, Helen Bourke-Taylor, Christine Imms, Dinah Reddihough, Liz Cox, Rob Carter, *Systematic review of the economic impact of cerebral palsy, Research in Developmental Disabilities, Volume 80, 2018, Pages 93-101, ISSN 0891-4222,*) Therefore, decreasing the severity of cerebral palsy through early and ongoing intervention reduces the lifetime cost of cerebral palsy.



at CPC has invested in both him and my family. They have enabled him to achieve so much.” Noah’s mum.

However, despite the clear and strongly evidenced benefits of early intervention (both economically and in terms of a child’s future outcomes), there is still a ‘wait and see’ approach taken in some cases with local practitioners only making referrals for specialist support, when milestones have been missed. Our consistent experience has been that the referral process can take several months, which has a detrimental and lasting impact on the babies, their future outcomes and their families, missing critical time during the period of greatest neuroplasticity when our intervention has the biggest impact.

We’ve made significant progress connecting with neonatal units to encourage really early referral and the number of referrals of babies who are at, or under 6 months old is steadily increasing. Our external communication with clinical professionals is ongoing to ensure that our services are widely known so that no child is left without the support they need – this is particularly true of our early intervention service, *Better Start, Better Future*. External communication also ensures we are kept abreast of developments within the sector. This includes our Centre Director and Head of Therapy meeting with the Paediatric Therapy Managers in each Local Health Board in Wales once a quarter. In addition, our Centre Director founded a Wales Cerebral Palsy Clinical Leads Group for those cerebral palsy clinical leads in each Local Health Board. This has resulted in a network we can link into to disseminate and collect information.

Partly as a result of this work, and partly related to the increased survival of children with chronic health conditions, disability and life-limiting illness, in 2022/23, we received an unprecedented number of referrals for *Better Start, Better Future* (76 babies from 48 in 2016/17). However, this increased demand, combined with rising operating costs, is making it increasingly difficult for us to see every child/family who needs us as *Better Start, Better Future* is funded entirely from our own resources and fundraising initiatives⁴. We are currently in discussion with Welsh Government about direct financial support, without which the service will not be able meet demand in future. Without us, the NHS and already stretched community teams would have to pick up the caseload and, as we are the only specialist centre in Wales for the treatment of cerebral palsy, if we fail to exist, there will be no specialist provision at all available for families - one of the most vulnerable communities in Wales.

⁴ Cerebral Palsy Cymru receives no direct revenue support from Welsh Government and has a strong track record of sustaining its funding levels, which has enabled the consistent expansion in therapy services over the past 31 years. Typically, just over 80% of our funding comes from charitable sources (including donations, gifts in wills, business partnerships, charitable trusts and retail activity through its 4 charity shops and online store). The remaining 19% is provided by contracts with all 7 of the NHS Wales Health Boards who have SLAs to provide specific provision per year, to a limited number of children, who would benefit from our specialist interventions. This funding has not increased since 2009. If it had kept pace with inflation, the 2009 contract would be £471,782 (£178,186 more than we are currently receiving).



Effectiveness of current measures to address inequalities/ barriers faced by certain groups

There is a body of evidence which indicates the huge unmet health and social care needs of individuals with cerebral palsy across the UK⁵ many of which CPC is working to address. This has been exacerbated by Covid:19 as mentioned earlier.

Achieving a child's full potential should never be reliant on how tenacious and assertive their parents/carers are, their financial circumstances, nor where they live in Wales. Disabled children and their families in Wales who require support should not be 'falling through gaps,' involved in overly bureaucratic processes nor in disputes between health, social care and or other professionals/organisations. A full report can be found here: <https://www.careinspectorate.wales/sites/default/files/2021-11/211129-national-overview-report-disabled-children-en.pdf>. Please also see: <https://www.nice.org.uk/guidance/ng213>

We know that there is huge inequity in accessing our services. After children leave our *Better Start, Better Future* early intervention programme at the age of 2½, they are only able to access further therapy if they are referred by LHBs as part of our SLA agreement. Limited budget means that only a small number of children (usually the most complex cases) are referred to us by community teams and many children therefore who could and would like to access our service miss out on continued and specialised treatment from Cerebral Palsy Cymru, as a centre of excellence, which could have a transformational impact on their future outcomes, independence and quality of living. An example of this would be children with hemiplegia (one side of body affected) who are often discharged from local services once they are up and walking. These children are the most physically able but can still have other significant needs in areas that don't always get seen until they are of school age. It is not equitable that this group cannot access further services to equip them for a greater level of independence in later life.

We are acutely aware of the need to be sensitive to different cultural and religious beliefs, as a disability diagnosis will have different meaning for parents from different cultural backgrounds. Indeed, in some circumstances, parents and/or carers may be less likely to seek treatment for their children. We have recently introduced a new, equalities monitoring system to understand better who we are reaching, and importantly who we are not reaching, with our programme. Based on current data, approximately 10% of beneficiaries identify as BAME for example. As we collect more data this will help to identify further any underrepresented groups and inform our wider external communications about the project as we seek to develop them through an Equality, Diversity, and Inclusion (EDI) lens. Additionally, a stakeholder mapping exercise for referrals will help to show where we need to be more targeted in our communications to disadvantaged groups.

⁵ This includes the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) *Each and Every Need* 2018 report, the European Academy of Childhood Disability (EACD) *Austerity Survey* 2016, the *Being Disabled in Britain 'A Journey Less Equal'* 2017 report by the Equality and Human Rights Commission, and several of the current National Institute for Health and Care Excellence (NICE) guidelines (NG62, .CG145) Schiariti, Verónica et al. 'Global COVID-19 Childhood Disability Data Coordination Collaborative Initiative of the International Alliance of Academies of Childhood Disability'. 1 Jan. 2023 : 1 – 12.



We are also aware from parents of the difficulty of the transition from paediatric to adult services for those living with cerebral palsy who have ongoing healthcare needs. The Welsh government set out an expectation that such a move, which is expected to happen around the age of 16, should be managed from around the time the child is 14 and there should be a named healthcare worker to oversee the transition. This is not always the case in practice.

RECOMMENDATIONS/ AREAS FOR FURTHER CONSIDERATION

1. We recommend that the Committee gives attention to the importance of early intervention, including the urgent consideration of direct funding to Cerebral Palsy Cymru to protect the future of its early intervention service.
2. We recommend that the Committee supports and accelerates the work being done to establish a register. Monitoring the incidence and prevalence of cerebral palsy across the country through a comprehensive register and surveillance programme will, in due course, reduce the incidence of contracture, dislocation and the need for surgery in children who have cerebral palsy. The register will provide data for service planning, research and evidence to improve neonatal care and quality of life for those living with cerebral palsy with an overall goal of reducing the incidence of cerebral palsy in Wales and informing appropriate service planning.
3. We recommend that the Committee works with Local Health Boards and the third sector, to review health provision for disabled children with a view to identifying unmet needs and gaps in service provision and takes action to address the deficits in health provision.
4. We recommend that the Committee considers increasing the training available to upskill and empower NHS community practitioners to make early referrals to our specialist service and to treat children with cerebral palsy to achieve long-term impact on, and benefit for, the child. We currently provide training and support to the clinical leads for cerebral palsy in each health board, to develop local expertise and to help foster and promote best practice Wales-wide. This training and support takes pressure off under-resourced Community therapy teams, which often refer their most complex cases to the Centre. However, funding is currently limited and inadequate for this work and there is a feeling amongst staff that cerebral palsy has been deprioritized in recent years due to financial pressures.
5. We recommend that the Committee implements plans to make available more emotional and mental health support, both for individuals who have cerebral palsy and for families caring for those with the condition.

I hope this submission has been useful for the inquiry and please do not hesitate to contact me if we can help or be further involved.

Yours sincerely

Jenny Carroll MA MCSP PGC(HE)
Centre Director/ Consultant Physiotherapist Cerebral Palsy Cymru
Co-Lead Cerebral Palsy Register for Wales



Appendix II

A Cerebral Palsy Register for Wales

With a project grant from the prestigious Moondance Foundation, the philanthropic trust of the Engelhardt family, Bobath Wales commenced work on the creation of a Cerebral Palsy Register for Wales in late 2017. The project is co-led by the charity's Centre Director and Consultant Physiotherapist, Jenny Carroll, and Consultant Paediatrician and Clinical Director of Women's and Children's Health for Powys Teaching Health Board, Dr Rachel Lindoewood. Dr Lindoewood had a Bevan Commission Fellowship to support this work.

The creation of a Cerebral Palsy Register is a crucial part of the charity's long-term Strategic Plan to increase and expand its service delivery for the children of Wales who have cerebral palsy. Specifically, the Register will:

- Enable a better understanding of the population in Wales living with cerebral palsy.
- Enable organisations involved in the care of children with cerebral palsy to better plan their services around the care and treatment needs of the child.
- Act as an agent for change which enables people with cerebral palsy and their families to be active participants and shape its development.
- Make a clinical difference for people in Wales who have cerebral palsy.
- Encourage research in Wales with and about individuals and populations who have cerebral palsy, their prevalence, needs, wants etc which will impact future generations.
- Add Welsh information to the European body of information through Surveillance for Cerebral Palsy Europe (SCPE), a European wide collaboration of 24 active registers.
- Help decrease the incidence of cerebral palsy.

The project is being driven forward by a steering group comprising 32 members, including service users and family representatives; a wide range of relevant professionals from 14 different clinical disciplines; in addition to Dr Heather Payne, Senior Medical Officer, Welsh Government, the Bevan Commission, the Congenital Anomalies Register (CARIS), and Digital Health and Care Wales (DHCW)). There are no national registers in Great Britain today, although Scotland now has a national hip surveillance programme; therefore, when established the Register will be the first national register of individuals who have cerebral palsies in Great Britain. We are already receiving requests from England to share our proposed model.

The creation of a Cerebral Palsy Register for Wales is a crucial, strategic step forward in understanding the precise population data and the level of need in Wales which, in turn, will inform treatment and research.