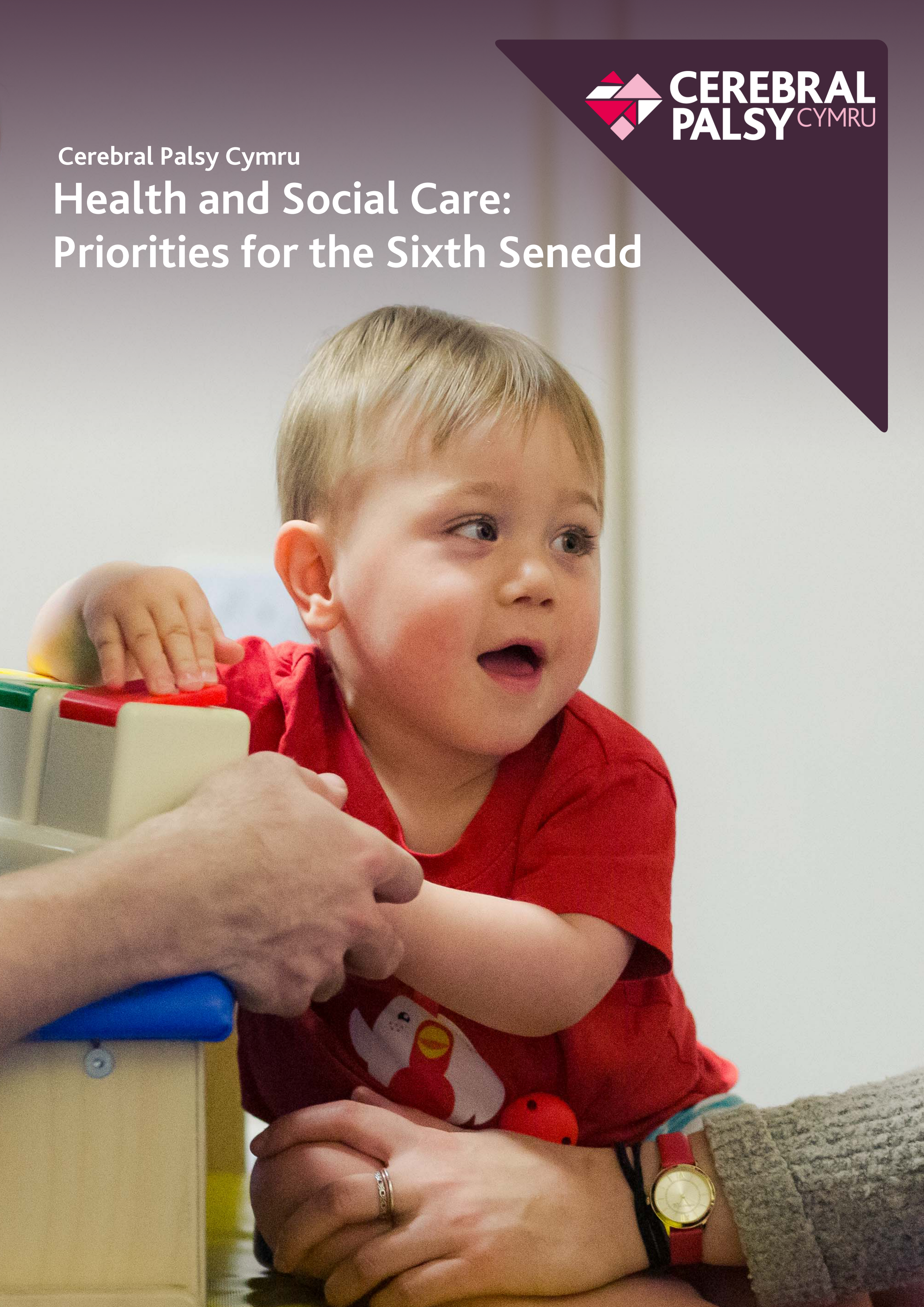
Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Flaenoriaethau'r Chweched Senedd

This response was submitted to the Health and Social Care Committee consultation on Sixth Senedd Priorities

HSC PSS 82
Ymateb gan: | Response from: Cerebral Palsy Cymru



Cerebral Palsy Cymru

Health and Social Care: Priorities for the Sixth Senedd

Dear Health and Social Care Committee

Health and Social Care: Priorities for the Sixth Senedd

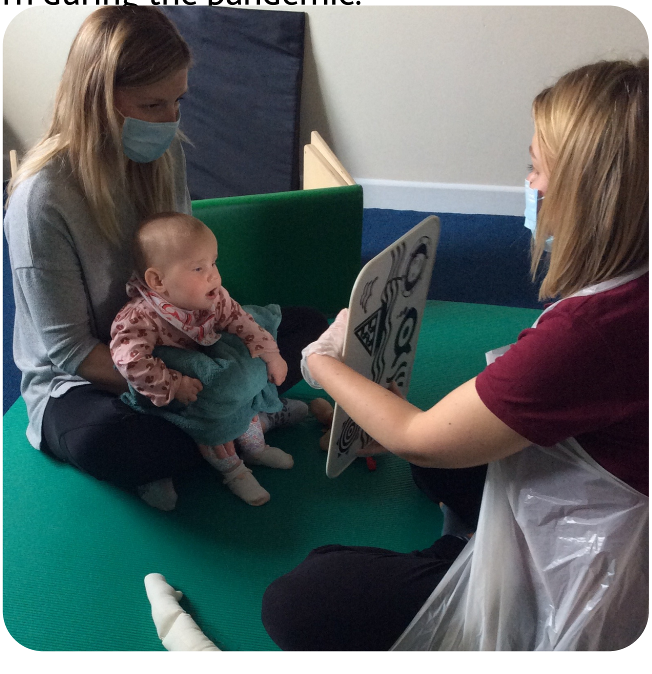
Cerebral Palsy Cymru are the voice of children and families with Cerebral Palsy in Wales. We provide specialist care, therapy and family support via our national centre of excellence for families in Wales.

Prior to 2020 we were known as Bobath Children's Therapy Centre Wales and before 1999 as Bobath Cymru. We have served the cerebral palsy community in Wales since 1992. We have a unique insight in the field of cerebral palsy and a global perspective and influence provided through our expert therapy team.

Jenny Carroll, Centre Director and Consultant Physiotherapist holds key roles in the International Alliance of Academies of Childhood Disability where she represents Europe on the Governing Council, chairs the Nomination Committee, is a member of the Global Professional Education Committee and a member of the Covid-19 Taskforce and Curator of the IAACD Knowledge Hub. She was also on the executive of the European Academy of Childhood Disability for seven years. She is part of an international teaching team.

Cerebral palsy is the most common physical disability in children. It is estimated that 6,000 people are living with cerebral palsy in Wales today, 1,800 of whom are children; and every year approximately 70 babies born will have the condition. The long lockdown and isolation has further impacted many of these children born during the pandemic.

Last year Cerebral Palsy Cymru provided therapy to 316 children living with cerebral palsy and their families. This means approximately 1384 children did not have access to a national specialist cerebral palsy service. Currently 101 of the estimated 210 children under 3 years of age living with Cerebral Palsy in Wales are seen under our Better Start Service. There is therefore an unmet need of 109 children with cerebral palsy not receiving this vital service.



We would like to make the case for the committee to consider the following as priority areas during the Sixth Senedd:

1. **Undertake an enquiry into support and services for children with or identified as at risk of cerebral palsy and their families.**

We would like the inquiry to look at the impact of the lockdown and isolation on children with cerebral palsy, especially those born during the pandemic, and to include the consideration of international best practice. The European Academy of Childhood Disability has already identified families of children living with cerebral palsy were disadvantaged from austerity measures https://onlinelibrary.wiley.com/doi/full/10.1111/dmcn.13978 and its survey on the effects of Covid across Europe identifies additional adverse effects of the Covid lockdown and can be found here https://edu.eacd.org/eacd-covid-19-surveys-report

1. **Consideration of the Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19 report, with specific recognition on children with disability. Cerebral palsy is the most common physical disability in children. In addition, we understand that a key priority for the committee over this Senedd term will be the impact of Covid, and we would like to request that any potential future inquiry is able to consider the impact of Covid on people and children with disabilities.**

We have included further information below on cerebral palsy and our work in Wales below, and we look forward to working with the committee during the sixth Senedd.

Yours sincerely,

Jenny Carroll
Centre Director/Consultant Physiotherapist MA MCSP PGC(HE)

Background information

Cerebral palsy is the most common physical disability in children. It is estimated that 6,000 people are living with cerebral palsy in Wales today, 1800 of whom are children, and every year approximately 70 babies born will have the condition.

Cerebral palsy is an umbrella term that describes a group of conditions affecting the developing infant or child's brain. Cerebral palsy results from damage to the brain that occurs during pregnancy; around the time of birth; or within the first two years after birth. It affects movement and posture, although these features are often accompanied by other difficulties. How cerebral palsy affects an individual will vary depending on the timing, extent, and location of the damage in the brain and the age of the child when the damage occurs. There is no cure for cerebral palsy, but specialist therapy intervention is proven to improve the quality of life of children living with cerebral palsy.

Supporting children with CP

Evidence demonstrates the importance of early years to all children and there has been much work to highlight this. This is particularly pertinent for children identified as at high risk of cerebral palsy, where early intervention can influence their long-term progress and the ultimate skills they will acquire to help them throughout their lives.

There is an early intervention window which substantially closes when a child reaches two years of age. Although the child can develop and progress after two, due to neural reorganisation and the loss of unused nerve cells, opportunities lost at this time cannot be regained.

Raising a child who has cerebral palsy is a major strain on parents and families resulting in an increased percentage of marital breakdown. Support even before a diagnosis can help build families' resilience and confidence in their own ability to cope and manage their baby's condition.

Long term this influences the whole family's mental wellbeing and potential to participate in society. Supporting children early in their development supports families and helps them stay together. All of this makes families and individuals more resilient and less dependent on the state for support across the lifetime of a child.

The long lockdown and isolation has significantly further impacted many of these children born during the pandemic.

Cerebral Palsy Cymru have developed an evidence-based, low tech, low-cost innovation - an early intervention programme called Better Start Better Future.

This programme supports families in managing their babies. It leaves families feeling more confident and resilient and supports the development of children at high risk of cerebral palsy. These individuals and families are then more able to manage their child's lifelong condition. Unfortunately, not all families find or are able to access this service.

Because we know.

Together we can make a difference.

Cerebral Palsy Cymru
1 The Courtyard
Ty Glas Avenue
Llanishen
Cardiff
CF14 5DX

02920 522 600
info@cerebralpalsycymru.org

Cerebralpalsycymru.org
Twitter @CP_Cymru
Facebook.com/CerebralPalsyCymru

Charity Number: 1010183
Limited Company Number: 02691690