



Cerebral Palsy Cymru
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By Email: Russell.George@Senedd.Wales

Russell George
Chair of the Health & Social Care Committee
Welsh Parliament
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14th February 2023

Dear Russell

Cerebral Palsy Register for Wales

We understand that the Senedd Health and Social Care Committee is currently considering its Forward Work Programme for Summer 2023. I am writing to you to ask you to consider including an inquiry into support and services for children with cerebral palsy and their families and especially the topic of the Cerebral Palsy Register for Wales in your programme.

A Cerebral Palsy Register for Wales is currently being developed and once fully implemented will have a major impact on health inequalities and prevention for those with cerebral palsy across Wales. There are approximately 6000 adults and children with Cerebral Palsy, with 70 born with Cerebral Palsy each year.

Cerebral palsy is an umbrella term that describes a group of conditions affecting the developing infant or child's brain. It is the most common physical disability in childhood. 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. How cerebral palsy affects a child will vary depending on the extent and location (in the brain) of the damage and the age of the child when the damage occurs. It is a lifelong condition, affecting movement and posture, although these features are often accompanied by other difficulties.

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Cerebral Palsy Cymru is a national centre of excellence for families in Wales with children who have cerebral palsy. Our mission is to improve the quality of life of all children in Wales living with cerebral palsy and our values of family, partnership, highest quality, and integrity underpin everything we do. We aim to achieve our mission through our vision which includes becoming an expert cerebral palsy service and an international specialist centre of excellence. We also aim to become a national resource for Wales and already support local NHS therapists providing more regular care for children with Cerebral Palsy and their families through consultation and training. We provide specialist therapy to children who have cerebral palsy and/or other allied neurological conditions from birth up to the age of 18. We provide services through our specialist team of physiotherapists, occupational therapists, and speech and language therapists who work together to offer transdisciplinary skills, so each child can benefit from their combined expertise. We make sure that the extended family and those who care for a child are involved in therapy sessions so that everyone knows how best to help whether at home or at school.

Our family support service offers a listening ear, advice and support through emotional, practical or financial issues. We share our knowledge and skills through collaborative working, courses, and national and international conferences. We also aim to share our multidisciplinary knowledge with families, but we also ask families to share their knowledge of their children with us so that we can learn and understand their children in different contexts.

We are currently working with NHS colleagues and other partners to establish the Cerebral Palsy Register for Wales, a clinician-led initiative, supported and developed by people who have cerebral palsy, their families, and representatives from each of Wales' local health boards, Digital Health and Care Wales, The Bevan Commission and Welsh Government. This supports recommendations from the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) Each and Every Need Report (2018) which highlights data collection as a way of driving improvement.

We believe a register would create a systematic approach to monitoring and understanding cerebral palsy in Wales and would support research. This in turn would help to improve the quality of life for those with cerebral palsy and enable Wales to become a more equitable and inclusive environment for them. A register would also enable better planning of health and care services for people with cerebral palsy by helping us to understand trends across Wales.

The plan for the register still requires further input from other stakeholders. We envision a phased roll-out of the register across Wales' health boards so that we can learn from experiences of how it operates in practice. We would be delighted if you would consider exploring the issue as part of your future work and would welcome any opportunity to engage with the Health and Social Care Committee about a Cerebral Palsy Register for Wales.

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This would be a fantastic opportunity for the Senedd to expand its understanding and evidence base around cerebral palsy and particularly how a register could improve the quality of life for those living with cerebral palsy. It would also be an opportunity for us to learn and consider input on the register from MSs and other stakeholders.

We look forward to hearing from you.

Yours sincerely



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