

8th December 2015

Public Petitions Committee Response

Petition PE01577: Adult Cerebral Palsy Services

'Calling on Scottish Parliament to urge the Scottish Government to develop and provide funding for a clinical pathway and services for adults with cerebral palsy'.

Capability Scotland Response

- In 1946 a group of parents and professionals came together to establish an organisation which could support children with cerebral palsy to go to school, get a job and look forward to a more independent life. That organisation grew to become Capability Scotland. Over the past 69 years we have been able to build on our strong heritage to provide modern, flexible services for people with cerebral palsy and a range of other conditions throughout Scotland.
- Our vision is that we will be a major ally in supporting disabled people to achieve equality and to have choice and control of their lives.
- Capability Scotland is also a campaigning organisation committed to using our influence to ensure disabled people achieve the same human and civil rights as the rest of society. We work with disabled people across Scotland to influence policy, legislation, practice and attitudes.
- Capability Scotland commissioned research from University of Glasgow looking at Ageing with Cerebral Palsy which was published in 2014. The findings formed part of the foundations for a 3 year research programme looking at access to Allied Health Provision for adults with cerebral palsy living in Scotland. This unreleased research provides a current position within our response to the PE01577 'Adult Cerebral Palsy Services' as requested by the Public Petitions Committee.

Ageing with Cerebral Palsy

Although the neurological injury associated with cerebral palsy is known to be non-progressive; the effects of living with this long-term condition are likely to manifest differently through the lifespan. The presence of motor impairments and other associated conditions are likely to impact on the ageing process and thus result in reduced overall function and quality of life if individuals do not receive the correct support and healthcare. It is important therefore, for healthcare providers to address the needs of children and adults who have cerebral palsy. Cerebral palsy should be recognised as a life-long condition. Research has highlighted the risks of developing secondary musculoskeletal and neurological symptoms and there is a growing body of literature about ageing and secondary conditions in adults with cerebral palsy. The literature documents many, sometimes chronic, physical changes and secondary conditions. The most commonly reported

age related changes relate to physical performance and the musculoskeletal system and pain and fatigue are also frequently reported as secondary conditions¹.

Prior to Capability Scotland's current research, only two studies have examined adult therapy provision in Scotland: i) Bobath Scotland and ii) Capability Scotland commissioned independent research to be conducted by the University of Glasgow, Strathclyde Centre for Disability Research (Paterson & Watson, 2014a; 2014b).

i) Bobath Scotland's research (Paterson & Watson, 2014a) evaluated an adult therapy pilot project. It was identified that there was limited service provision to support changing needs of adults with cerebral palsy within health and social care services. The short intervention provided therapy sessions for 22 adults with cerebral palsy and attempted to ascertain the extent and need for adult therapy. Qualitative information was evaluated and adults reported that the pilot project had met their needs and requirements both in terms of physical and psychological health. Adults and therapists also reported physical changes associated with ageing, poor provision of healthcare and equipment in mainstream services and lack of knowledge to meet the needs of individuals living with this condition. It was concluded that adults experience deterioration in their health and that mainstream services were not meeting the changing needs of this population. The Bobath Scotland adult therapy pilot project provided individuals with 'hope and positivity' (Paterson & Watson, 2014a p. 13).

ii) Capability Scotland's research examined the experiences and perceptions of older people with cerebral palsy (Paterson & Watson, 2014b). Interviews were conducted with 26 adults living in Scotland. Health professionals were also interviewed. The findings from this research showed that as people with cerebral palsy age, their impairment and the extent to which they are affected by their condition changes. Furthermore, it was concluded that services and support for adults do not recognise or take account of these changes. It must be noted however that the individuals who participated in this study were 55-70 years of age, with one individual 46 years of age. The age for transition from childhood to adult services in Scotland tends to be 16-18 years of age. With research suggesting that access to therapy provision reduces in adulthood and that transition between services may be a problem, it is important to consider the experiences and perceptions of ageing and therapy provision at all ages throughout adulthood.

Current research being undertaken by Capability Scotland aims to extend this previous work and examine ageing and experiences of therapy provision for adults of all ages with cerebral palsy in Scotland (unpublished; Palmer, 2015). Findings from this research show that 80% of adults with cerebral palsy reported experiencing changes to their condition with age². These changes were reported throughout adulthood and were not limited to older adults. The most frequent changes reported included changes in mobility, increased pain and fatigue. It also appears that these changes were unexpected, with 67% of adults reporting that they had never been spoken to by a health professional about potential changes related to ageing and cerebral palsy.

Findings from Capability Scotland & Bobath Scotland's research (detailed above) support the petitioner's statement that 'cerebral palsy is not a static condition'. Evidence suggests that adults with cerebral palsy in Scotland are experiencing secondary ageing, that is individuals are not only facing the effects of ageing, they are also experiencing accelerated ageing due to the effects of living with a long-term condition¹. Changes with age are likely due to the long-term

¹ Andersson & Mattsson, 2001; Ando & Ueda, 2000; Bottos, Feliciangeli, Sciuto, Gericke & Vianello, 2001; Engel, Jensen, Hoffman & Kartin, 2003; Hilberink, Roebroek, Mieuwstraten, Jalink, Verheijden & Stam, 2007; Hirsh, Gallegos, Gertz, Engel & Jensen, 2010; Jahnsen, Villien, Aamodt, Stanghelle & Holm, 2004; Morgan, Soh & McGinley, 2014; Nieuwenhuijsen, van der Laar, Donkervoort, Nieuwstraten, Roebroek & Stam, 2008; Opheim, Jahnsen, Olsson & Stanghelle, 2009; Paterson & Watson, 2014a; 2014b; 2013; Sandström, Alinder & Oberg, 2004; Schwartz, Engel, & Jensen, 1999; Strauss, Ojdana, Shavelle & Rosenbloom, 2004

² 104 adults with cerebral palsy completed the questionnaire. Adults had a range of needs and were wide spread across Scotland.

musculoskeletal and neurological nature of their condition. It is important therefore to acknowledge cerebral palsy as a lifespan disability and provide appropriate health and social care to support these individuals. Unfortunately, however, evidence suggests that adults with cerebral palsy in Scotland are not receiving the specialist care they need to maintain their health and quality of life.

Therapy Provision Landscape for Adults with Cerebral Palsy Across Scotland

As part of our ongoing research programme, Capability Scotland has recently mapped the therapy provision landscape for adults with cerebral palsy across Scotland (due for release in 2016). For the purposes of this work, therapy provision related to Allied Health therapy, namely Occupational Therapy (OT), Physiotherapy (Physio) and Speech and Language Therapy (SALT). In order to enhance evidence with regards to the therapy landscape in Scotland, data was collected from Allied Health Professional (AHP) leads across Health and Social Care Partnerships (HSCPs) and Freedom of Information (FOI) requests were submitted to all health boards and local authorities. This contributed to the identification of the most appropriate pathways and criteria for services for adults with cerebral palsy.

The emerging outcomes of this mapping work support the petitioner's statement that 'there is not a national clinical pathway or therapy for adults with cerebral palsy'. The maps of therapy provision across Scotland for OT, Physio and SALT identify disparities in service provision between HSCPs in Scotland and also for individuals with and without learning disabilities (LDs). This finding is similar to the findings presented by Horridge et al (2015) where quality of healthcare was reported to differ for children and young people with cerebral palsy across districts in the North East of England. The maps identify that suggested referral pathways for adults with LDs are via multi-disciplinary LD teams, whereby a holistic approach is taken. In comparison, a variety of referral pathways are recommended for adults without LDs depending on individuals' postcodes. Criteria for accessing services also differ depending on the type of therapy input required. Furthermore, some HSCPs are unable to suggest the best referral pathway and thus individuals are told to visit their GP to ask for the most appropriate referral. Whilst it is understood that adults without LDs may be more independent, Capability Scotland would suggest that these adults still require expert advice and knowledge to support them living with a long-term condition. The differences in access to therapy provision for adults with and without LDs would indicate disparate standards of care and unequitable access to service provision across Scotland.

The FOI responses gathered as part of the research from health boards and local authorities also support the petitioner's statement that 'there is not a national clinical pathway or therapy for adults with cerebral palsy'. NHS health boards and local authorities were asked about current resources to support the needs of adults with cerebral palsy within their area. Current resources varied between health boards and local authorities, with some reporting that resources to support adults are not condition specific. Capability Scotland welcomes the fact that health and social care services across Scotland are beginning to work to a social model of disability which focuses on functional difficulties rather than medical diagnoses (thus enabling a person-centred approach). However, this does not ensure that resources are currently matching individual need.

Capability Scotland would agree with the petitioner's statement that 'Cerebral palsy is not treated as a life-long condition by the NHS'. This can be substantiated by the FOI responses we received where we asked NHS health boards whether cerebral palsy is categorised and/or treated as a long-term condition. Responses identified differences across Scotland. Only 3 out of 14 health boards confirmed that cerebral palsy was categorised and/or treated as a long-term health condition.

Differences in how cerebral palsy was categorised were also evident between local authorities, with many stating that they do not categorise individuals with this condition or disabilities by diagnosis but rather focus on individual needs. Capability Scotland believes it is important to

formally acknowledge the long-term, neurological nature of the condition as this may help to increase awareness and encourage individuals, families/carers and professionals to acknowledge and take responsibility for cerebral palsy and changes which can occur with age, ultimately improving quality of life. One participant in our research states:

'More specialists need to be trained with in depth knowledge of the condition and a passion for helping people with cerebral palsy. Cerebral palsy desperately needs to be recognised as a lifelong condition and given the same recognition as other conditions'

Experiences of Therapy Provision Across Scotland

Capability Scotland's current research aims to examine the lived experience of accessing and receiving therapy services in Scotland. Questionnaires were completed by adults (aged 21+) with cerebral palsy and AHPs from across Scotland.

Adults with Cerebral Palsy

Adults with cerebral palsy were asked about access to therapy provision in their adult lives. For those who reported that they had experienced changes with age (80%), 92% of these individuals reported that they had wanted to access therapy. Of those who had wanted to access therapy, only 29% had been successful. Reported success rates in accessing therapy were higher for individuals who reported additional diagnoses (e.g. hearing impairment, LD and visual impairment).

Adults who reported being unsuccessful in accessing therapy were asked to select reasons for being unsuccessful from a list of responses. The most frequent responses for being unsuccessful when accessing therapy were:

1. The therapy input I need is not provided in the public sector
2. I am not sure where to access the therapy provision I need
3. Health professionals have been unsure where to refer me to for therapy input.

Adults with cerebral palsy reported how satisfied they were with their overall therapy provision experience. Mixed experiences were reported. Just less than half of adults with cerebral palsy without an additional diagnosis reported that therapy provision was either poor or very poor.

Overall, it appears that adults with cerebral palsy living in Scotland have unmet health needs. However, as previous research has demonstrated, it is important to manage and maintain health for adults with cerebral palsy to prevent and/or mitigate the secondary ageing process. In the AHP National Delivery Plan 2012-2015, the Scottish Government have acknowledged that AHPs play a crucial role in the delivery of rehabilitation and enablement approaches that underpin safe, effective, affordable and sustainable health and social care services. Focus on enablement by AHPs, shifts focus away from professional dependency and towards supported self-management and resilience. Adults with cerebral palsy and/or their family/carers should therefore be able to access AHP services when necessary and gain skills and knowledge in how to manage their condition. Regular and timely contact with AHPs can lead to significant reductions in unnecessary admissions to hospital and diminish dependency on care services, which ultimately results in significant savings for health and social care (Scottish Government, 2012). Participants in our research also commented on this:

'Having cerebral palsy does not stop when you become an adult and having therapy helps people to be independent for longer'

'There is no information/help on accessing services & therapies for people with Cerebral Palsy specifically, once they reach adult services'

In response to the petitioners comment about waiting for long periods of time to receive services and having difficulty accessing specialist services, qualitative data collected by Capability Scotland shows that other adults with cerebral palsy are having similar experiences. In interviews conducted with adults with cerebral palsy, there appeared to be a general feeling that waiting times to receive services were too long. Individuals also reported having to access private therapy provision because what they needed was not available and they wanted to access specialist knowledge.

'I have not accessed any therapy because I don't know how to get the therapy I need. You are put on long waiting lists so by the time you get there, changes have already happened'

'My body was getting really bad, I didn't have physio for three weeks and I was on every painkiller, that's not any quality of life is it...so that's what made me go find him (a private therapist)...there was nothing they could do (statutory service)...because they don't do maintenance physio.'

Furthermore, qualitative information collected from AHPs³ also supports the petitioners experience with regards to long waiting lists to receive services and lack of specialist services.

'Very limited physiotherapy service available in the NHS. Long term nature of condition and limited resources means a lot of emphasis is placed on self-management. Often people need more intensive support, hands on treatment or specialist equipment to make a real difference to their function'

'I see our service providing transition service from paediatrics and ongoing input / review over the long term as required working well and being very beneficial. There is an inequality in specialist nursing provision for all disabilities including cerebral palsy e.g. MS, MND, stroke, Parkinson's specialist nurse but no input for CP and "other" neurological disabilities'

Allied Health Services and Professionals

With regard to current research, AHPs across Scotland and across sectors were asked about therapy provision for adults with cerebral palsy. Survey responses showed that most professionals believe that therapy provision for adults with cerebral palsy in Scotland is 'adequate'. When thoughts about therapy provision were compared between those AHPs working in different sectors, differences emerged. When AHPs thoughts about therapy provision were compared between professions, differences were also shown. AHPs rated provision as 'adequate' and/or 'poor'.

AHPs were also asked what they thought about the organisation and signposting to inform professionals and adults with cerebral palsy about therapy provision. The majority of AHPs rated the organisation and signposting to therapy services as 'adequate' and/or 'poor'. Thoughts about the organisation and signposting to therapy services also differed between sectors. When AHPs ratings about the organisation and signposting to therapy services were compared between professions, differences were also shown. These findings along with quotes from AHPs support the petitioner's statement that 'When a person with CP leaves school all these services stop'.

'Once people reach 18 or leave education it is very difficult to access input. When I try to find local service for my client(s) to liaise or refer on, there is no clinical pathway to follow'

'Big difference between paediatrics and adults. No services available for adults with CP who do not have a learning disability'

³ 138 AHPs completed the questionnaire. The questionnaire was completed by occupational therapists, physiotherapists and speech and language therapists working across sectors in Scotland.

AHPs who completed the questionnaire appeared to have a good understanding of the changes which can occur in adulthood for individuals with cerebral palsy. Capability Scotland believes this knowledge should be utilised and expanded upon. Adults with cerebral palsy with or without a LD are entitled to therapy provision that meets their needs and from professionals who understand about the long-term, neurological nature of the condition. All AHPs regardless of the sector they work in should be provided with training to support them when providing therapy for adults with cerebral palsy/physical disabilities. All of the above findings from AHPs suggest that more can be done to improve healthcare provision, organisation and signposting to services and support for professionals delivering services to adults with cerebral palsy.

Further Comments

In the SPICE briefing, it was noted that 'The Scottish Government funds the National Neurological Advisory Group (NNAG)...The NNAG is currently looking at pathways across neurological conditions with a view to publishing a library of good practice pathways that can be adapted to meet the needs of individual boards'. As acknowledged by Stephanie Fraser, CEO of Bobath Scotland, 'The problem with cerebral palsy is that it does not fit very easily under the neurological umbrella. It is not the same as epilepsy, Parkinson's, motor neurone disease or any of those other conditions'. Currently, there are no Managed Clinical Networks in Scotland which cover cerebral palsy within their remit and further unpublished data gathered by Capability Scotland would support Stephanie Fraser's statement. Similarly, clinical standards for neurological health services have not focused on cerebral palsy as a neurological condition (NHS Quality Improvement Scotland, 2009). Although it is understood that limited neurological conditions were looked at within these standards, across policy documents, cerebral palsy is rarely acknowledged as a long-term, neurological health condition.

Capability Scotland recognises that AHPs and healthcare staff play an important role in maintaining good health and quality of life for adults with cerebral palsy. Research conducted to date identifies gaps in therapy provision across Scotland and suggests that services tend to be reactive rather than proactive in their approach. Capability Scotland has 69 years of knowledge and experience of cerebral palsy developing a understanding of the challenges faced by those living with the condition and we would support the petitioners call for 'the development of a national clinical pathway and services for adults with cerebral palsy'.

Contact Us

Thank you for the opportunity to comment on this public petition. If you require more information on this response, please contact:

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References

- Anderson, C., & Mattson, E. (2001). Adults with cerebral palsy: A survey describing problems, needs, and resources with special emphasis on locomotion. *Developmental Medicine & Child Neurology*, 43, 76-82
- Ando, N., & Ueda, S. (2000). Functional deterioration in adults with cerebral palsy. *Clinical rehabilitation*, 14, 300-306
- Bottos, M., Feliciangeli, A., Sciuto, L., Gericke, C., & Vianello, A. (2001). Functional status of adults with cerebral palsy and implications for treatment of children. *Developmental medicine & child neurology*, 43, 516-528
- Engel, J. M., Jensen, M. P., Hoffman, A. J., & Kartin, D. (2003). Pain in persons with cerebral palsy: Extension and cross validation. *Archives of Physical Medicine and Rehabilitation*, 84(8), 1125-1128
- Hilberink, S. R., Roebroek, M. E., Nieuwstraten, W., Jalink, L., Verheijden, J., & Stam, H. J. (2007). Health issues in young adults with cerebral palsy: Towards a life-span perspective. *Journal of Rehabilitation Medicine*, 39, 605-611
- Hirsh, A. T., Gallegos, J. C., Gertz, K. J., Engel, J.M., & Jensen, M. P. (2010). Symptom burden in individuals with cerebral palsy. *Journal of rehabilitation research and development*, 47(9), 863-876
- Horridge, K., Tennant, P. W. G., Balu, R., & Rankin, J. (2015). Variation in health care for children and young people with cerebral palsies: A retrospective multicentre audit study. *Developmental Medicine and Child Neurology*, 57(9), 844-851. doi: 10.1111/dmnc.12740.
- Jahnsen, R., Villien, L., Aamodt, G., Stanghelle, J. K., & Holm, I. (2004). Musculoskeletal pain in adults with cerebral palsy compared with the general population. *Journal of Rehabilitation Medicine*, 36(2), 78-84
- Morgan, P. E., Soh, S-E., & McGinley, J. L. (2014). Health-related quality of life of ambulant adults with cerebral palsy and its association with falls and mobility decline: A preliminary cross section study. *Health and quality of life outcomes*, 12(132)
- NHS Quality Improvement Scotland (2009). *Neurological health services: Clinical standards*. Retrieved from http://www.scottishneurological.org.uk/content/res/final_QIS_standards.pdf
- Nieuwenhuijsen, C., van der Laar, Y. M., Donkervoort, M., Nieuwstraten, W., Roebroek, M. E., & Stam, H. J. (2008). Unmet needs and health care utilization in young adults with cerebral palsy. *Disability and Rehabilitation*, 30, 1254-1262
- Opheim, A., Jahnsen, R., Olsson, E., & Stanghelle, J. K. (2009). Walking function, pain, and fatigue in adults with cerebral palsy: A 7-year follow-up study. *Developmental medicine and child neurology*, 51, 381-388
- Paterson, K., & Watson, N. (2014a). *An evaluation of Bobath Scotland's adult therapy pilot project*. Unpublished manuscript
- Paterson, K., & Watson, N. (2014b). *Ageing with a lifelong condition: The experiences and perception of older people with cerebral palsy*. Unpublished manuscript
- Palmer, L. E. (2015). *Researching therapy provision for adults with Cerebral Palsy across Scotland: Enhanced Evidence Report*. Unpublished manuscript
- Sandstrom, K., Alinder, J., & Oberg, B. (2004). Descriptions of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disability and rehabilitation*, 26(17), 1023-1031
- Schwartz, L., Engel, J. M., & Jensen, M. P. (1999). Pain in persons with cerebral palsy. *Archives of Physical Medicine and Rehabilitation*, 80(10), 1243-1246
- Scottish Government (2012). *AHPs as agents of change in health and social care. The National Delivery Plan for the Allied Health Professions in Scotland, 2012-2015*. Retrieved from <http://www.gov.scot/resource/0039/00395491.pdf>
- Strauss, D., Ojdana, K., Shavelle, R., & Rosenbloom, L. (2004). Decline in function and life expectancy of older persons with cerebral palsy. *NeuroRehabilitation*, 19, 69-78