

PE1577/J

Petitioner submission of 11 May 2017

This is in response to the evidence session held on the 16th of March 2017 with the Minister for Public Health and Sport and members of the Clinical Priorities Team.

I would like to emphasise that there is no transition from the paediatric service to an adult service. I did not fall through the gaps, and an adult service for cerebral palsy does not exist. I have attended the annual Bobath Conference for 3 years now and it is clear from talking to adults with the condition and their families and other healthcare professionals that this is the case across Scotland. This is why it is extremely important to establish a national pathway of care which provides continuity and specialist care to every adult in Scotland with cerebral palsy.

I have attended meetings with both the Clinical Priorities Team and the Minister for Public Health and Sport, during which we discussed a variety of issues; however, the strategy of establishing localised pathways was never discussed either with me or Murdo Fraser MSP. I am very concerned with this approach because I know that a number of health boards are in debt and unlikely to establish a service for adults with cerebral palsy when there are pressures on acute services. This may lead to one area making it a priority and another health board area doing nothing. This is why Scottish government needs to prioritise the needs of adults with cerebral palsy at a national level. If this is only led by local health boards and integrated joint boards then there is a danger that a postcode lottery would exist. Furthermore, the health minister and deputy chief medical officer described cerebral palsy as a complex condition and the way it manifests itself is unique to the individual. This is one of the reasons why they did not feel that establishing a national clinical pathway would work for adult cerebral palsy. That could be said of all other neurological conditions such as MS, Parkinson's and motoneurons disease, but they all have pathways and are supported by specialists within the NHS.

I was astounded that the deputy to medical officer thought it was possible that charities could hold health boards to account. This is not possible as some charities will receive Scottish government funding and will not want to rock the boat. Therefore the only agency that can hold a health board to account is the Scottish government themselves.

In addition, I am still sceptical about the time scale, because when I met with the Clinical Priorities Team they did say that it may take 5 to 10 years to implement a pathway. I just hope that the Minister does keep to her commitment that this will not take 10 years to happen. Nevertheless, I know this will take time to implement because there are no consultants, nurses, or physios that specialise in cerebral palsy as an adult condition. Therefore, the health minister will need to look at workforce planning to establish a pathway/service that will respond to the complex needs of adults with cerebral palsy.

I was also concerned to hear that Elizabeth Porterfield stated that although cerebral palsy was a complex and specialist condition, there are neurological physios within the NHS who are trained to deal with a wide variety of conditions, including cerebral

palsy. This is not the case: the physios that I have seen on the NHS do not understand my condition and in the worst case could do more harm than good. If the physio concerned has not previously done a paediatric rotation they may have never come across cerebral palsy at all.

I urge the Scottish Government to consult with the paediatric experts who specialise in children with the condition, and other healthcare professionals, in order to build a service/pathway that will meet the needs of an adult with cerebral palsy. They are the experts. That is why I see a paediatric physio privately to manage my condition, but I shouldn't have to do this. There should be a specialist service provided to support me with my condition throughout life as it changes and deteriorates. I know that the government has consulted with Bobath Scotland, but they have limitations because they are not an NHS funded service. Adults with the condition do have to self fund to receive treatment, plus Bobath are based in Glasgow which is not accessible to every adult in Scotland with cerebral palsy. This is why NHS services have to be established and accessible and support their needs in the right way.

I would welcome the opportunity to address the committee to explain these issues further. I would also like to suggest that it may be helpful that my mother gives evidence to the committee because she has a different perspective on these issues as a parent.

I look forward to working with the committee and the Scottish government to establish continuity of care and a robust national approach and pathway for all the adults in Scotland with cerebral palsy.

Yours sincerely,