PE1179/R

Healthcare Policy and Strategy Directorate Healthcare Planning Division | Long Term Conditions Unit

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By Email

Fergus D Cochrane Esq Clerk to the Committee Public Petitions Committee TG.01 The Scottish Parliament EDINBURGH EH99 1SP

Your ref: Petition PE1179 3 February 2010

Dear Fergus,

CONSIDERATION OF PETITION PE1179: ACQUIRED BRAIN INJURY

In my letter of 27 October 2009, I undertook to make arrangements to meet the Petitioner to discuss the issues raised in the Petition, and to provide the Committee with a summary of that meeting.

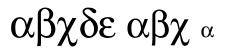
Those representing BrainIAC at the meeting were:

- Ms Helen Moran, Chair;
- Mr Mark Ziervogel, Vice-Chair;
- Mr Alan Agar, Secretary; and
- Mr Neil Sloan, Treasurer.

I was accompanied by:

- Dr Alan Carson, Consultant Neurospychiatrist and Chair of the national Managed Clinical Network (MCN) for Acquired Brain Injury;
- Mr Douglas Gentleman, Consultant in Neuro-Rehabilitation and Convener of the Scottish Head Injury Forum; and
- Ms Fiona Maxwell, Network Manager, national Neurosurgery Managed Service Network.

The main concerns expressed by the BrainIAC representatives were that recognition of Acquired Brain Injury (ABI) as a separate care category would produce a better service; that there were huge variations between Council services, even in adjacent local authority areas; that there was a need to audit deficiencies in service; and that some people with ABI experienced a diminution of service simply because they had reached the age of 65.





Dr Carson indicated that the ABI MCN fully agreed with the spirit of the Petition and explained that the difficulties in providing services stemmed from the fact that far more people now were surviving with ABI. People were also sustaining their injuries at a younger age, and these considerations meant that survivors' problems were more complex, with provision of services becoming more expensive. A further factor was that care packages involved joint health and social care funding, and that presented major challenges because dedicated budgets were not available for specific conditions such as ABI, and having it designated as a separate category could therefore run the risk that any pool of dedicated funding identified would be insufficient.

We also suggested to the BrainIAC representatives that there were practical difficulties in defining what exactly should be covered within a separate category of ABI, and that the idea of creating a separate care category ran counter to the central aim of the Health Directorates' work on long term conditions, which was to treat people as people, rather than defining them by their condition, in order to make sure the totality of their care needs were addressed.

The main issue was, therefore, finding the most effective way of achieving the Petitioners' aim of improving services. We expressed the view that the work of the ABI MCN in mapping services, which represented the sort of audit BrainIAC was looking for, was a particularly effective way of highlighting the variation in provision, especially as that information was readily available on the Network's website. The standards which the Network had been developing would be an effective mechanism for promoting consistency of approach in all parts of the country.

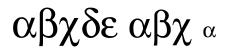
As part of treating ABI as a long term condition, we agreed to make sure that each NHS Board's executive sponsor for long term conditions was aware of the work which the MCN was undertaking.

The MCN was about to publish a paper on the epidemiology of ABI, and also intended to look at issues such as the numbers affected by traumatic ABI. That work would give statutory agencies a clearer idea of the size of the the problem, and so enable them to put in place plans for the provision of the right kind of services. The MCN also had a role in stimulating academic interest in research into ABI.

The MCN was also looking at access to community rehabilitation, since that was a key aspect of the standards it had developed. We undertook to make sure that the Rehabilitation Officers who have been appointed in each NHS Board to take forward the Framework for Adult Rehabilitation in Scotland were made aware of the rehabilitation needs of those with ABI, so that they could include provision of those services, or the lack of them, in the mapping exercise which they were carrying out in each NHS Board.

Although the MCN was currently a Managed *Clinical* Network, emphasising the priority it had felt had to be given to improving the health care of those with ABI, it clearly recognised the importance of developing into a Managed *Care* Network, the different designation signalling an intention to include social and other local authority forms of care within the Network's structure. Part of that work would include the development of standards relating to social care. The MCN was setting up a sub-group to take that work forward over the next 2-3 years, and Dr Carson urged BrainIAC to identify someone who could represent it on that sub-group, to help ensure that the work focused on the issues that were of greatest significance to people with ABI, as well as identifying the main targets for service improvement in a way that would allow progress towards achieving them to be measured and published.

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Dr Carson also welcomed BrainIAC's existing participation in the work of the MCN, since the way the Network brought together all those responsible for providing services for people with ABI, and their families and carers, offered a mechanism for identifying more efficient ways of working that also met people's needs more effectively.

The MCN also had an important part to play in providing people with information both about ABI and the services which were available. There was a clear role for BrainIAC in making sure that that information was provided in a way which people could understand easily.

We shared BrainIAC's concern about people over 65 with ABI getting access to clinical neuropsychology, given that cognitive and emotional impairment in that age group can require these specialist skills. This is an issue which the MCN could help to address.

We therefore see the work of the ABI MCN as the best mechanism for addressing BrainIAC's concerns, as well as offering an effective mechanism for BrainIAC's involvement in future development of services.

I hope the information in this letter will be of assistance to the Committee in its further consideration of the Petition.

Yours sincerely,

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