

Frank McAveety MSP
Convener, Public Petitions Committee
TG.01
The Scottish parliament
Edinburgh
EH99 1SP

14th March 2009

Dear Mr. McAveety,

**Open Petition PE1179 - Brain Injury Awareness Campaign
Comments on letter of 5th Feb 2009 from the Minister for Public Health**

1. We wish to express **BrainIAC's** disappointment at the Minister's refusal to accept Acquired Brain Injury (**ABI**) as a new separate and distinct health and community care client category, and request that the Public Petitions Committee press the Minister to review this decision.
2. We concur with the Minister that services should be based on individual need and not a specific condition. However, the performance framework network for better health outcomes will fail if there is not a clear **definition** of the problem; this is currently the case with **ABI** where there has been a consistent failure by service providers, particularly in the community, after the acute hospital care and initial rehabilitation. This petition was presented because of the poor general level of service provided to the **ABI** client group.
3. **BrainIAC** would argue that where clinical entities have been defined e.g. Cancer, Coronary Heart Disease, Stroke, Dementia and many others - national guidelines are in place, services provision is audited and significant improvements in service delivery have been achieved, for which credit must go to the Scottish Government. **BrainIAC** ask for similar focussed attention which could still be delivered through the Managed Clinical Network (**MCN**). **Indeed**, the Minister makes the point in her second bulleted paragraph that **MCNs** have already been developed for longstanding client group categories to bring about more integrated services and better information for those who require support.
4. We appreciate that the current focus of the **MCN** for **ABI** is , by definition, clinical and that it may well broaden its activity into the area of social care provision. **BrainIAC** would welcome such a move. However, our experience suggests both that there will be an unacceptable delay in the development of the necessary "care networks", and that their effects will be rather limited unless our proposal for a new separate and distinct health and community care client category is introduced.
5. **BrainIAC** notes that to date, no response has been received from the **Association of Directors of Social Work** to our petition. Your Committee already has responses to our petition from the statutory/professional clinical providers and non-statutory/voluntary/patient and carer organisations on their views with regard to **ABI** services. As the long-term community social care service, essential for many of the **ABI** client group, should be the responsibility of Local Authorities, we feel it important that the views of the **Association of Directors of Social Work** and/or **COSLA** on **ABI** services should also be obtained, especially as this is a crucial part of the jigsaw. Our experience is that these services vary from a few excellent providers to many where dedicated **ABI** services are non-existent. As there is no separate health and community care category of

acquired brain injury Local Authorities squeeze such care into Physical Disability or Mental Health categories which do not meet **ABI** sufferers' needs.

6. In your original briefing paper created by **SPICe**, it was noted by The Chartered Institute of Public Finance and Accountancy that Local Authorities had accounting structures which currently subdivided Social Work spending into: children & families, older people, people with physical or sensory disabilities, people with learning disabilities, people with mental health needs, and people with addictions /substance misuse. This **SPICe** document also noted, as advised by the Scottish Government, that *"those with an **ABI** are usually counted within statistics on physical disability, possibly as a result of the need that individuals with an **ABI** require equipment and adaptations."* **BrainIAC** believes that this attitude underlies many of the difficulties in obtaining appropriate services for the **ABI** group. We suggest that the way forward is for the new health and care category as defined in Petition 1179 to be accepted. This would obviate the accounting confusion outlined above and make it both easier for local agencies to track spending on **ABI**, and facilitate people with **ABI** getting the support and services they need.

7. All the voluntary organisations that responded to the Public Petitions Committee on our **BrainIAC** Petition were in favour of recognition of **ABI** as a care category - these are sometimes the only organisations that deal directly with the brain injured and their carers on a day-to-day basis. The statutory service providers and planners did not favour a new care category for **ABI** - yet one of the major problems in obtaining care is that individuals with brain injuries do not fit currently used care categories for Mental Health or Physical Disability which results in an inferior service for the **ABI** client group.

8. With regard to the Minister's closing paragraph, the contention that local agencies have a responsibility to deliver services that meet the needs of their local population does not apply as a rule in relation to the **ABI** client group.

9. Given the new ethos for health in Scotland that sees the general public and staff of the NHS as partners and co-owners in the NHS, it follows that modern health care should be patient-oriented if not patient-led, where patients and carers are encouraged to be genuine partners in the delivery of their care through a commitment to patients' rights, real involvement and representation with a voice that is heard. **BrainIAC** has identified a failure to provide uniformly satisfactory health and social care services for the acquired brain injured and their carers. It believes this deficiency would be addressed if **ABI** were recognised as a separate clinical and social care category, and requests the Committee to progress our petition through the most appropriate parliamentary mechanisms.

Yours truly,

Helen Moran, Chairperson

For, and on behalf of, the Brain Injury Awareness Campaign (**BrainIAC**) March 2009

[Via email from **Helen Moran, BrainIAC Chairperson** (serviceuserforum@gmail.com)
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