

Neurological Alliance of Ireland Submission to Second Independent Monitoring Group: A Vision for Change

The Neurological Alliance of Ireland welcomes the opportunity to comment on progress on a Vision for Change as outlined in your letter of 17th September 2009.

A Vision for Change notes the requirement for mental health services to provide for the mental health needs of people with neurological conditions. In particular, the strategy highlights the need for neuropsychiatry services in specific neurological conditions, including acquired brain injury, early onset dementia, and epilepsy and in the management of non specific or unexplained neurological symptoms.

The strategy correctly notes that neuropsychiatry service needs are largely unmet in Ireland and the existing liaison psychiatry mental health services often lack the specific expertise to manage these conditions. Neuropsychiatric expertise and treatment is purchased from abroad but should be provided here in Ireland. Greater recognition of the mental health needs of people with neurological conditions living in the community, and increased development of acute neurology services in coming years will lead to increased demand for neuropsychiatry services.

Specific Issues in the Development of Neuropsychiatry Services in Ireland

A Vision for Change provides an estimated requirement for specialist neuropsychiatry services of 30-35 referrals per 100, 000 population based on neuropsychiatric needs in a range of conditions including acquired brain injury, early onset dementia and unexplained neurological symptoms. The report also recommends the development of a challenging behaviour unit in Ireland to meet the need of specific groups of people with neurological conditions, including acquired brain injury.

Recommendations for a Proposed Model of Neuropsychiatry Service Provision

The strategy recommends the establishment of a working group to plan neuropsychiatric services in both of the national neuroscience centres in Dublin and Cork with two multidisciplinary neuropsychiatric teams developed nationally to work from these neuroscience centres. The report identifies the need for a clinical lead for the development of regional neuropsychiatry services. In addition, the strategy highlights the requirement for a national inpatient neuropsychiatry centre ideally based in or near a national neuroscience centre with links to neurology and neurorehabilitation services.

Less specific recommendations are made on the meeting the continuing care needs of neuropsychiatry patients, noting that these are “best provided in consultation with

rehabilitation medicine services and recovery and rehabilitation mental health services”. The report notes that mental health services for older persons are best positioned to address the continuing care needs of early onset dementia patients.

Progress on development of Neuropsychiatry Services

Member organisations of the Neurological Alliance of Ireland are concerned about the lack of progress and a specified timeline on the development of the model of neuropsychiatric services outlined in a Vision for Change.

According to a report published by Amnesty in September 2009¹ no progress has taken place on the development of the two recommended multidisciplinary teams within each of the national neuroscience centres. Consultation by NAI with Neuropsychiatry in these centres indicates the ongoing lack of neuropsychiatry beds and key members of the neuropsychiatry team including neuropsychiatric nursing, psychotherapy and psychology services. There is no timeline available for the development of a national inpatient neuropsychiatry unit.

The lack of specialist neuropsychiatric services continues to impact significantly on the quality of care available to people with neurological conditions in Ireland.

Need to Consider the Model of Neuropsychiatric Services in A Vision for Change

The NAI is concerned that the development of specialist neuropsychiatric services still represents only one aspect of meeting the mental health needs of people with neurological conditions. A Vision for Change puts forward this point by noting that the proposed model for development of neuropsychiatry services outlined in the strategy “will still not service the needs of those who need neuropsychiatric expertise”. There is a critical need for mental health services to respond to the needs of people with neurological conditions. It is notable that A Vision for Change does not make any recommendations for the development of neurological expertise in community mental health services within its recommendations for the development of neuropsychiatry services. Given the emphasis of the strategy that delivery of mental health services should take place primarily at community level, the NAI urges that this oversight be addressed within the current review of the strategy.

There is a need to expand the model of neuropsychiatry services outlined in a Vision for Change to include recommendations for meeting the mental health needs of people living in the community who will not come into contact with specialist neuropsychiatric services, including:

- the need to promote increased awareness and expertise in the management of neurological conditions among staff in general mental health services, particularly community mental health teams
- greater awareness of the mental health needs of people with neurological conditions in residential, day centre and other settings with appropriate specialist services and personnel where required

¹ Review of Government Spending on Mental Health and Assessment of Progress on Implementation of A Vision for Change. September 2009, Amnesty (Ireland)

-development of guidelines for the management of mental health issues in common neurological conditions with agreed protocols for referral to mental health services

Overall Progress on Implementing A Vision for Change

A comprehensive review of current deficits in mental health staffing to meet the recommendations of a Vision for Change are outlined in the Amnesty report Review of Government Spending on Mental Health Services (September 2009) This continues to impact significantly on the ability of mental health services to respond to the needs of all service users, including people with neurological conditions. For example, gaps in team development in older persons services (only 23 teams out of the recommended 42) impact on their ability to meet the needs of people with dementia.

Lack of a Framework for the Management of Neurological Conditions in Ireland

The development of a co-ordinated response to meeting the mental health needs of people with neurological conditions is just one aspect of the need for an integrated national approach to the management of neurological conditions. Previous reports in this area have focused on the development of acute neurology services (which have not in themselves been implemented) with no overall framework for meeting the needs of people with neurological conditions at all stages of the care pathway. This has resulted in a fragmented approach to the development of services for people with neurological conditions in Ireland which continues to impact significantly on the quality of life of these individuals and their families. The Neurological Alliance of Ireland wishes to take this opportunity to recognise the benefits of a strategic approach to the management of mental health in Ireland represented by a Vision for Change and emphasise the critical need for a similar response to the management of neurological conditions.

Conclusion

A Vision for Change recognises the need for specialist services to respond to the mental health needs of people with neurological conditions and dearth of these services in Ireland in response to growing demand. The report makes a series of recommendations for the development of specialist neuropsychiatric services, including multidisciplinary teams in each of the main neuroscience centres, a national inpatient neuropsychiatry centre and a unit for the management of challenging behaviour.

The Neurological Alliance of Ireland is concerned at the lack of progress on each of these recommendations and the lack of an agreed timeline for the development of these services. The continued lack of specialist neuropsychiatric services continues to impact significantly on the quality of care and treatment of people with neurological conditions in Ireland.

The Neurological Alliance also highlights the need for the model to be broadened to include recommendations for meeting the mental health needs of people with neurological conditions within general mental health services, particularly in the community.

The NAI emphasises the lack of a strategic framework for meeting the needs of people with neurological conditions in Ireland at all stages of the care pathway which continues to curtail the development of specialist neurological services and their links with other areas of the health service, including mental health.

Member Groups of the Neurological Alliance of Ireland

Full Members

Acquired Brain Injury Ireland

Alzheimer Society of Ireland

Aware

Brainwave: The Irish Epilepsy Association

Brí

Cheshire Ireland

Dystonia Ireland

Enable Ireland

Friedrich's Ataxia Ireland

Headway

Huntington's Disease Association of Ireland

Irish Association for Spina Bifida and Hydrocephalus

Irish Chronic Pain Association

Neurofibromatosis Association of Ireland

Parkinson's Association of Ireland

Post Polio Support Group

Volunteer Stroke Scheme

Irish Motor Neurone Disease Association

Migraine Association of Ireland

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

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Myasthenia Gravis Association of Ireland

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Irish Institute of Clinical Neurosciences