Persons with acquired brain injury: a disabled diaspora

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The *Vision for Change* Document states that *"Neuropsychiatry service needs are largely unmet in Ireland and where they are met, it is by existing liaison psychiatry mental health services. Additional expertise and treatment is purchased from abroad but should and can be provided here"*.[1]

Acquired Brain Injury (ABI) prevalence rates of up to 2% have been described in the US.[2] In Ireland, *Vision for Change* estimated a neuropsychiatry need in ABI of approximately 80 cases per 100,000 population annually.[1] The risk of ABI is greatest between the mid-teen years and mid-twenties, and again in the elderly, with males at particular risk. The commonest causes are transport-related injuries, followed by falls which are more frequent in older age groups.[3] Residual deficits in cases of mild, moderate and severe ABI have been estimated at 10%, 67% and 100% respectively.[4]

Psychiatric sequelae are common and may develop several years after the initial injury. A 30 year follow-up study of 60 ABI patients found a lifetime prevalence of 26.7% for DSM-IV major depression.[5] Kreutzer *et al* found a prevalence rate for DSM-IV major depression of 42% at 2.5 years post-injury.[6] Anatomical regions implicated in the aetiology of psychosis, such as the temporal lobes, prefrontal cortex and hippocampus, are particularly vulnerable to acquired injury, and ABI has been estimated to account for 1-17% of all cases of schizophrenia.[7]

Certain subgroups of people with major mental illness are known to be overrepresented in prison populations. In the remand setting, the disproportionate accumulation of persons with psychotic illness has already been reported.[8] A recent comprehensive survey of the Irish prison population found prevalence rates of 7.2% with lifetime history of ABI among sentenced prisoners.[9] A population of remand prisoners with ABI and learning disabilities also exists, often charged with relatively trivial offences, and vulnerable in the prison setting. These patients are generally male, relatively young and often homeless. Such prisoners may have difficulties in meeting bail requirements and can spend unusually long periods on remand due to difficulties locating appropriate treatment and placement facilities. This is particularly the case where supported accommodation or placement in specialist inpatient centres is required. The accumulation of these individuals in the Criminal Justice System may reflect the inability of overstretched services elsewhere in the system to meet existing need.

A number of agencies exist in the community to provide support and assistance to people with ABI-related difficulties. BRI (The Acquired Brain Injury Advocacy Association) strives to ensure that all those affected by an acquired brain injury have the best possible quality of life, and works to achieve this by prevention, increasing public awareness and promoting joined-up services for those with ABI. Headway Ireland has offices in Dublin, Cork, Kerry and Limerick, as well as an information centre in the south east, and provides individual and group day services, psychological (including neuropsychological) services and rehabilitation programmes. The Peter Bradley Foundation provides assessments, assisted living, community rehabilitation and case management services. It also offers information and support to families of people with acquired brain injuries. The National Rehabilitation Hospital has a neuro-behavioural clinic and inpatient services providing multidisciplinary input from rehab-neuropsychology, neuropsychiatry and other services.

While the majority of persons living with ABI-related disabilities function well and lead rewarding lives in the community, a proportion require additional supports. Individuals suffering from complications of ABI may have complex needs, often beyond the skills and service remit of general adult mental health services.[6] In particular many services have limited access to neuropsychological assessment. Advocacy networks emphasise the difficulties experienced by some people with such difficulties in accessing appropriate mental health services.

Difficulties in accessing mental health care and appropriate accommodation may be further exacerbated by homelessness. Pre-morbid ABI is particularly common amongst homeless populations. A New York study found 40% of homeless individuals with a schizophrenia-like psychosis had a history of ABI.[10]

Supported residential facilities are required where individuals are unable to live independently. Some will require such placements as part of a step-down process from inpatient units, while others will require longer-term rehabilitation. Standard psychiatric community hostels typically struggle to meet the needs of persons with ABI and comorbid psychiatric illness. While agencies such as the Peter Bradley foundation provide a limited number of residential placements (approximately 50), these are insufficient in number and may have difficulty in addressing the needs of individuals exhibiting more markedly challenging behaviour. Independent-sector agencies have developed supported community residences to meet this need. Such facilities provide 24 hour support and rehabilitation for persons with ABI.

Challenging behaviour is not uncommon among persons

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with ABI, although serious violence is rare. Behavioural treatments can be highly effective in the management of aggressive behaviour in such individuals. The National Rehabilitation Unit, among its 46 beds allocated to ABI, provides a *nine-bedded inpatient rehabilitation unit for persons with* behavioural difficulties after ABI. Access to specialised inpatient units with specific skills in the behavioural management of severe challenging behaviour is extremely limited in Ireland, although one such unit has recently been opened in the independent sector. When made available on an individual basis such services have typically been purchased in the United Kingdom, in units that also accommodate Irish Learning Disabled patients with challenging behaviour. The annual cost of such a placement is in the order of several hundred thousand euros per patient. Clearly it is less than ideal that such individuals should spend extended periods geographically separated from family and friends. Eventual return to Ireland remains difficult due to the shortage of appropriate long-term residential facilities for people with persistent challenging behaviour after ABI. The number of this "disabled diaspora", while unknown, is such that there is a clear economic argument for the development in Ireland of specialised challenging behaviour units skilled in the behavioural management and rehabilitation of persons with ABI.

Vision for Change recommended the development of neuropsychiatric multidisciplinary teams and recognised the need for a challenging behaviour unit in Ireland. It is apparent that these recommendations need to be implemented as a matter of urgency. In planning any such service, account must be taken of numbers already occupying such facilities abroad in addition to the existing need in Ireland. Planning must also incorporate the need for step-down facilities and longer-term supported accommodation in the community as well as supports for the majority who live independently with family support in the community.

*Placement in forensic psychiatric settings is rarely indi*cated and it is important that prisons and forensic psychiatric and rehabilitation hospitals do not become proxies for services currently unavailable in Ireland. There is a need for close integration between mental health service providers, service users, forensic services, rehabilitation medicine and other agencies, to meet the complex needs of those with acquired brain injuries.

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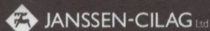

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