

## **Response from Neurobehaviour Clinic at National Rehabilitation Hospital to Submission to Second Independent Monitoring Group: A Vision for Change**

### **Prepared by:**

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### **1. Introduction: Brief History and Summary of Neurobehaviour Clinic at NRH.**

- 1.01 There is a growing awareness that unrecognised and untreated neuropsychiatric problems can be a considerable source of distress to patients with chronic neurological conditions, seriously affecting their quality of life not only for them but also for their families and carers. Consequently, it is essential that we plan and develop patient-centred multidisciplinary care to properly meet their neurobehavioural needs.
- 1.02 According to Agrawal *et al*, (2008), in the UK there is no comprehensive population based epidemiological study capturing the incidence and prevalence of neuropsychiatric illnesses and such studies are likely to be complicated by difficulties with case definition and case ascertainment. Data from Scandinavia (Fink *et al*, 2003), suggests that the prevalence of mental disorders in new neurological patients is 55% (64% in-patients & 39% out-patients) and the lifetime prevalence was over two thirds. Agrawal *et al*, (2008) also refer to the prevalence of neuropsychiatric problems in neurological disorders including ABI (18% rising to 40% if all neurobehaviour problems are included), Epilepsy (30-40%), Parkinson's Disease (40%), MS, Stroke and Huntington's disease etc have also been shown to have high neuropsychiatric comorbidity.

- 1.03 Agrawal *et al*, (2008) argue that an ideal neuropsychiatry service should be accessible, contain an appropriate skill mix and be adequately staffed as well as be allied to both mental health and neuroscience services. They also propose that because of the limited availability of trained professionals, a ‘hub and spoke’ model should be adopted, where there is a central, regionally based neuropsychiatry/neurobehavioural service (possibly allied to a neuroscience centre) acting as a hub that works closely with local Psychiatrists. We would add that Clinical Psychologists and other mental health professionals need to be included into teams who run a local specialist interest clinics for neurobehavioural problems and who require specialist access to local tertiary advice and opinion.
- 1.04 In 1999, the NRH established a Neurobehaviour Clinic scheduled one day per month and served by clinical specialists from Neuropsychiatry, Rehabilitation Medicine and Neuropsychology. This is a national service which receives referrals ranging from General Psychiatry, Neurology, General Practitioners; Community based agencies (e.g. ABBI and Headway) and other health care personnel. Over the last 10 years we calculate that we have undertaken approximately 1,000 consultations. The most frequent clinical issues include; (1) the complex constellations of neurobehavioural symptoms that frequently lead to misdiagnosis and inappropriate use of medication, (2) scarcity of appropriately trained staff and services that patients can be referred onto in order to undertake the recommendations made at the Neurobehaviour Clinic, (3) poor availability of psychotherapy, especially cognitive behaviour therapy services for example, anger management and (4) timely access to relevant services.
- 1.05 We frequently use teleconferencing as a way of facilitating that patients, families and relevant professionals in order to (1) include as best as possible all relevant personnel and family/carers in the consultation, (2) to reduce the stress, time and cost of travel especially those living beyond the immediate Leinster region and (3) because of the demand on the service, it allows reviews and monitoring, especially of medication changes, to be undertaken in area a timely fashion.
- 1.06 Most patients have on average 2/3 assessment sessions over a 12/24 month period.

## **2. Response to the Second Independent Monitoring Group for a Vision for Change:**

- 2.01 We propose that the term Neurobehaviour Clinic is adopted as a service descriptor. The Neurobehaviour Clinic is a tripartite clinic that includes specialists in Neuropsychiatry, Neuropsychology and Rehabilitation Medicine and was devised in order to accurately respond to the neurological, psychological, rehabilitation and psychiatric issues presented by patients with Acquired Brain Injury (ABI) at the

NRH. The overlap between the various neurobehaviour symptoms tends to make the clinical presentation complex and multifaceted, hence the need for clinical evaluation and management from a range of clinical perspectives.

- 2.02 In our opinion, the need for Neurobehaviour services is most commonly required for patients who have sustained an ABI or have been diagnosed with Epilepsy or Dementia. Within each of these diagnostic categories there can be unexplained and non-specific clinical signs, which can straddle between and beyond these three diagnostic categories. As noted above, our Neurobehaviour Clinic include specialists in Neuropsychiatry, Neuropsychology, Rehabilitation Medicine and experts from other specialities for example, Geriatrics, Neurology, Forensic Psychiatry etc. should be involved in order to provide neurobehavioural services depending on the clinical cohort being served. We are cognisant that our opinion does not necessarily represent the opinion of our colleagues in these clinical specialities and we are not claiming to represent them in this submission and we would recommend that their opinion should be sought in order to capture the spectrum of clinical issues that can be associated with Neurobehaviour problems.
- 2.03 Vision for Change recommends that there should be two National Multidisciplinary Teams providing a National Neuropsychiatry Service. Their locations are not specified but Dublin and Cork appear to be implied. There is also a proposal for a 6-10 bed Neuropsychiatric Unit and again the location not specified and the criteria used for establishing a 6-10 bed unit for a population of 4 million are not clear.
- 2.04 In light of our comments in 2.02 above, we propose that three National Neurobehaviour Clinics are established that are dedicated to the three most prevalent clinical groups who require neurobehavioural expertise – Epilepsy, ABI and Dementia.
- 2.05 These Clinics should include at a minimum, clinicians with expertise in Neuropsychiatry and Neuropsychology and depending on the clinical cohort specialism in Rehabilitation, Neurology and Geriatrics etc.
- 2.06 Regarding the proposal to develop a Neuropsychiatric Unit (p.77 Vision for Change) of 6-10 beds, for the last 15 years the NRH has provided a 9-bed unit for patients with a variety of neurological, neuropsychiatric and neuropsychological symptoms including for example, behaviour and mood disturbance, post-traumatic amnesia, amnesic syndromes and complex cognitive problems. This unit can accommodate patients who not only have these symptoms but also those who are wheelchair dependent, hoist transferred, peg fed and who require high level of expert medical and nursing care. The NRH unit can accommodate at any one time, 1-2 patients with very challenging behaviour, 4 moderate challenging behaviour and 3 ‘pleasantly’ disorientated/wanderer patients.
- 2.07 We propose that in addition to the Unit described above, that rather than propose a single Neuropsychiatric Unit comprising of 6-10 beds, a Neurobehaviour Service

should be based on the most frequent clinical needs and these range from patients who require 24 hour in-patient specialist care to supporting those who are living in the community. In light of this, we propose that such a unit/service should be organised as a service that encompass the following levels of care:

- 2.08 ***Highest level of Need:*** For the group of patients with the highest level of need we propose that a Neurobehaviour Unit needs to address the needs of patients presenting with Severe Challenging Behaviour (e.g. a Unit similar to the Kemsley Unit in Northampton, UK). For a population the size of Ireland, it is estimated that a 10 bed unit would be required and this should be ideally located within a psychiatric hospital with clinical support from Neuropsychiatry, Neuropsychology, and Rehabilitation Medicine and other specialists as indicated. In addition, the needs of the Forensic Psychiatric population with acquired brain injury need to be addressed and dedicated services established, but again our colleagues in Forensic Psychiatry and Psychology need to be consulted about this.
- 2.09 ***Medium level of Need:*** For a mild to moderate challenging behaviour service where patients still require intensive medical, therapy and nursing care (e.g. patients who have tracheostomies, peg –fed, reduced mobility, disorientated etc), we propose that the 9 bed unit at NRH is adequate when it has its full staff compliment.
- 2.10 ***Low level of need/supported living:*** For patients who have made gains following their rehabilitation programme and are able to take on more independent living but still require specialised support and behaviour management, a Transitional Living Unit (TLU) is indicated where there is a balance between promoting independence while also providing support as required. We propose that this should be similar to the Rehabilitation Training Unit (RTU) at NRH but with appropriate levels of personnel who can provide supervision, if required over a 24 hour period.

### **3. Conclusion**

- 3.01 We would welcome and recommend further consultation about how best to address the issues and needs outlined above. The problems experienced by patients with neurobehavioural problems can often fluctuate over the course of their diagnosis and in response to specific events and in turn our clinical priority is to address these needs in a responsive and clinically accurate way.

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Page 5 of 5

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