Health Research Board's submission to the Second Independent Monitoring Group for *A Vision for Change*

The Health Research Board (HRB) welcomes the opportunity to make a submission to the Second Independent Monitoring Group for *A Vision for Change*.

The activities of the HRB, in particular the Mental Health Research Unit (MHRU) of the HRB, relate to Chapter 19 of *A Vision for Change* – Mental Health Information and Research. There are 13 recommendations in this chapter, 11 of which bear on activities of the MHRU – 19.3-19.6 relates to data collection and mental health information systems, 19.7 calls for a national morbidity survey to determine the prevalence of mental health problems in the population while 19.8-19.13 relate to mental health research and its required infrastructure.

Data collection and mental health information systems [Recommendations 19.3-19.6]

The National Psychiatric Inpatient Reporting System (NPIRS) managed by the HRB provides annual statistical data on the activities of the inpatient psychiatric services and provides data on those who use services. In addition, quarterly reports on specific performance indicators for the mental health services are provided based on the NPIRS database. This database along with regular census data provides the basic data for policy, planning, management of the mental health services in Ireland. The MHRU responds to many requests for data from these databases from a broad range of national and international stakeholders and we encourage use of the databases for research, in accordance with relevant protocols.

It is widely recognised that similar epidemiological and health service data is required for the community services. Supported by the Department of Health and Children and CMOD, the HRB is working in partnership with the HSE in developing and implementing a mental health information system which captures data on all elements of secondary and tertiary mental health services. The system is called WISDOM and is being implemented as a Proof of Concept in Donegal, it will then be evaluated. The evaluation will feed forward to national decision making regarding a mental health information system. Without such a system it is difficult to see how priority information for service planning and development can be gathered and researched. Of critical importance in the area of health information is the continued delay in implementing a unique identifier and advancing an electronic patient record. Such developments would make it possible to follow pathways to care for individuals across the health service and would provide legible, up-to-date patient information for clinicians.

A Vision for Change calls for the development of an agreed national minimum data set for the mental health services. The Mental Health Commission in collaboration with the MHRU developed such a draft minimum mental health data set, which is embedded in WISDOM. However, we are disappointed to report that discussions with the HSE regarding a national mental health minimum dataset have not progressed.

Although NPIRS data and the census data only cover inpatient services, MHRU research using this data has provided some interesting information to inform implementation of *A Vision for Change*. For example, predictions were made in the last inpatient census report regarding the timescale for the closure of psychiatric hospitals should long stay patients be resettled in the community (Daly & Walsh, 2006). A follow-up of this data however showed that the resettlement of new long stay patients was not advancing as predicted resulting in the protracted closure of such hospitals (Daly & Walsh, 2009). Unless current practice changes as advocated in *A Vision for Change,* it will be a number of years before this population leaves psychiatric hospitals and such hospitals can close because of the lack of suitable alternatives. In addition, the research points to the lack of suitability of inpatient psychiatric

care for the continuing care of those with an organic mental disorder without accompanying behaviour disorder and those with a primary diagnosis of intellectual disability. In accordance with policy recommendations, the continuing requirement for the development of rehabilitation services to cater for the broad needs of those who remain in psychiatric hospitals is of the utmost importance.

Regarding the resettlement of long stay patients and community residential services a report by the HRB and MHC showed that these facilities required a significant amount of reorganisation and development in order for them to meet best practice in recovery oriented mental health services (Tedstone Doherty, Walsh & Moran, 2007). This report makes a number of recommendations that could inform the implementation of *A Vision for Change* in relation to rehabilitation and recovery, provision of community residential services, future provision of housing for this clientele and the need for a multisectoral approach to service delivery.

The NPIRS data continues to show that alcohol addiction accounts for a significant proportion of admissions to psychiatric units, contrary to policy recommendations (Daly, Walsh & Moran, 2008). Furthermore re-admissions continue to account for large numbers of admissions suggesting that community services in this area and in the area of dual diagnosis require further development. The increased, although non-optimal, provision of, and focus on, community-based services does not appear to have diminished the need for inpatient treatment, pointing to a system based very much on a revolving door phenomenon (Daly, Tedstone Doherty & Walsh, 2007). This appears particularly true in Ireland given the continuing high proportion of readmissions to inpatient facilities.

A national morbidity survey [Recommendation 19.7]

We are happy to report that the second HRB National Psychological Wellbeing and Distress Survey (HRB NPWDS) has been completed (Tedstone Doherty & Moran, 2009). As recommended in *A Vision for Change* [19.7 calls for a national morbidity study] - this survey provides information on mental health problems in the population. In addition, information is provided on associated health service use, and associated social and physical limitations. In the absence of a national morbidity study, the HRB NPWDS provides important information at the population level. There is a need to identify those most likely to develop mental health problems and the type of help they are most likely to seek. In addition, the characteristics of those who are not willing to seek help need to be identified. These groups can then be targeted for education and health promotion programmes. The MHRD survey of psychological distress in the general population provides answers to some of these questions (Tedstone Doherty & Moran, 2006; Tedstone Doherty et al, 2008). It also provides basic information on the use of general practitioners for mental health problems. Findings show that the general practitioner followed by family and friends are the most likely source of support for psychological distress. Since the publication of *A Vision for Change* development in the area of the mental health in primary care has been disappointing. Yet the majority of mental health problems are treated in primary care. Given the current economic climate and the probable negative effects this will have on population mental health, there is urgent need to develop services in this area as recommended in Vision.

Mental health research [Recommnedations 19.8-19.13]

A Vision for Change describes a framework for providing accessible, community-based specialist services for people with mental illness. Yet research from the MHRU shows that many of the activities provided by mental health services for those with enduring mental illness are provided in isolation and in psychiatric day centres increasing stigma and exclusion of these individuals from the wider community (Tedstone Doherty et al, 2007). In addition, many of the activities that are provided in the community such as day outings occur in large groups as opposed to a more individualised approach. One way in which this could be improved is a switch to the provision of activities that are currently offered by the mental health services in a segregated manner, to provision in community

facilities. It would better reflect a recovery oriented approach if these activities were run on small group basis and whereby individuals were encouraged to develop personal hobbies and interests.

The Family Support Study by the MHRD, showed that families of those with enduring mental illness suffered from isolation and the lack of social support (Kartalova O'Doherty et al, 2006). The families in this study highlighted a number of factors that could help prevent isolation and exclusion at various stages of their relative's illness. All participants expressed the need for an approachable mental health services contact, a key worker, or a 'mediator' between families, service users, and mental health services.

The lack of recovery-oriented mental health services has been recognised by *A Vision for Change* and evidence from the MHRU research findings reflects this (Kartalova O'Doherty et al, 2006; Tedstone Doherty et al, 2007). The routes to recovery for those experiencing mental ill health, until recently, has been poorly researched in Ireland. The MHRD will shortly publish a three-year study on the users' perceptions of their journey to recovery (Kartalova O'Doherty et al, in preparation). The main aim of this study was to develop a coherent theory of recovering from mental health problems capable of guiding and informing mental health practice, research and health promotion. *A Vision for Change* recommends that services become recovery oriented and this report, based on service users' reports, can provide information on what recovery means to those with mental health problems and how services can be designed to facilitate recovery.

On foot of the above, we suggest priorities from Chapter 19 *Vision for Change* for implementation for 2010 should include:

12.2 Some 38 rehabilitation and recovery CMHTs should be established nationally, with assigned sector populations of 100,000.

12.5 Rehabilitation and recovery mental health services should develop local connections through linking with local statutory and voluntary service providers and support networks for people with a mental illness to support community integration.

12.6 All current staff within the mental health system who are appointed to rehabilitation and recovery teams should receive training in recovery-oriented competencies and principles.

19.3 Measures should be put in place to collect data on community-based mental health services

19.4 In accordance with recommendation in the National Health Information Strategy, an electronic patient record should be introduced with a unique identifier for every individual in the state.

19.10 A national mental health services research strategy should be prepared.

19.11 Dedicated money should be provided by the Government for mental health services research.

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