Submission

Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Bill 2012

25th January 2013

Orygen Youth Health Research Centre welcomes the opportunity to provide the following submission to the Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Bill 2012.

This Bill establishes the framework for the National Disability Insurance Scheme (NDIS) and the National Disability Insurance Scheme Launch Transition Agency. The first stage of the scheme will benefit more than 20,000 people across five state and territory jurisdictions and Orygen Youth Health (OYH) welcomes this sensible approach towards implementing what will be a complicated and ambitious programme of change encompassing multiple jurisdictions across clinical and social care provision.

OYH is Australia's largest specialist youth mental health organisation, and comprises a specialised youth mental health clinical service, an internationally renowned youth mental health research centre and an integrated training and communications programme. OYH's clinical programme provides a comprehensive range of clinical services to young people aged between 15 and 25 years who are experiencing serious mental health issues. The OYH Research Centre aims to further our understanding the biological, psychological and social factors that influence the onset, remission and relapse of mental illness in order to find better ways to prevent or reduce their impact on young people by developing innovative therapies and service models, while the focus of the OYH Training and Communications team is on translating our research and clinical innovation into practice in real-world settings. Our unique structure and our focus on emerging mental disorder and early intervention has led to major advances in mental health care for young people in the early stages of a serious mental illness being implemented world-wide, and OYH is now considered an international leader in the youth mental health field.

The National Disability Insurance Scheme Bill 2012 (the Bill) sets out the objects and principles under which a National Disability Insurance Scheme will operate, including giving people with disability choice and control over the care and support they receive, and giving effect in part to the United Nations *Convention on the Rights of Persons with Disabilities*. The Bill sets out the process for a person becoming a participant in the scheme, how participants develop a personal, goal-based plan with the Agency, and how reasonable and necessary supports will be assured to participants. What is not clear is how far and to what

degree the existing arrangements in place for an individual's care are to be replaced or enhanced by the NDIS and to what extent the provision of support sits alongside the provision of clinical care.

While we appreciate that further detail will be provided in the Regulations, it would be useful to consider the proposed legislation's understanding of 'support' or 'early intervention' and certain aspects of existing recovery-based care. OYH's guiding principle of early intervention is to support the independence and social and economic participation of people with mental ill-health with the aim of providing the young person with the best possible opportunity for recovery and a return to a normal, productive life. Similar criteria guide the existing language in the proposed legislation and while this is to be applauded greater clarity needs to be provided on the scope of the Bill and its relationship with the existing arrangements for support and recovery-based care provided at OYH. With this in mind, we have provided some examples of where we think the NDIS could contribute to the expansion of supports and services for young people under our care.

There is also some contention around the language associated with the Bill. In our experience young people have been disempowered by the idea that their mental ill-health is a fixed disability. Mental ill-health does cause disability, often severe but after treatment it is not necessarily permanent. The language as it stands leads to an impression of permanency and a loss of hope or at the very least a reluctance to embrace the prospect of some form of recovery. In Victoria we have seen the psychiatric disability rehabilitation and support *services* (*PDRSS*) experience difficulties connecting with young people (they have found it both non-applicable and stigmatising). Some thought needs to be put into how the NDIS will engage with the very people it is hoped it will provide the most benefit for in terms of communicating its relevance to their circumstances and practical needs.

Opportunities for the NDIS

The psychotic illnesses, including schizophrenia, are the most severe and disabling of all mental disorders. In Australia, the recent Second National Survey of People Living with Psychosis has estimated the prevalence of psychotic illness at 4.5 cases per 1000 people aged between 18 and 65 years in any given year, or approximately 70,000 people Australia-wide[1]. Most people with a psychotic illness experience multiple relapses with periods of good or partial recovery in between episodes, although around one third of patients have ongoing chronic illness. Regardless of the course of their illness, the majority of people with a psychotic disorder have significant disability, with 85% relying on Government pensions as their main source of income[1]. Much of the disability associated with these illnesses appears within the first few years after their onset[2]. Because 75% of people living with a psychotic illness experience their first episode before 25 years of age[3], one of the major factors contributing to this disability is the interruption to the affected young person's social,

educational and vocational development that occurs at this particularly sensitive stage of life as they begin to establish themselves as independent adults.

Over the last two decades, increasing evidence has accumulated in favour of early intervention in order to minimise the impact of psychosis on the individual, their family and society more widely, and support the individual in their recovery process[4]. Australian researchers and clinicians are at the forefront of the early intervention movement world-wide, and the Australian Government has recognised the importance of early intervention and is actively committed to seeking to reduce delays in accessing treatment for the full spectrum mental disorders experienced by young people, initially with the establishment of **headspace** in 2006, and more recently, with the funding of a staged rollout of up to 16 EPPIC-style early psychosis services nation-wide. These services provide comprehensive, evidence-based mental health care that is most appropriate for the young person's stage of illness, in youth-friendly settings with a unique culture of care that considers their unique developmental needs, actively includes their families, and emphasises an optimistic approach to recovery and the future. The available evidence shows that such services are not only highly valued by clients and their families, engage young people much more successfully than standard services, and deliver better clinical and functional outcomes for young people, but that they do so at significantly lower cost than that of standard models of care[5-9].

While the medical needs of those in the early stages of a serious mental illness are currently covered by Medicare and state-based mental health funding, these young people have complex needs and will benefit greatly from dedicated supports and services that address two areas of particular need that are not covered by the current funding models: a strong focus on psychosocial and functional recovery to allow the young person to stay in, or resume, their education or employment and better manage their illness, and for those who need it, an extended tenure of care within a specialist early intervention service.

Psychosocial and functional recovery programmes are crucial components in maximising and maintaining recovery and enabling people to live independently. Data from the Second National Survey of People Living with Psychosis illustrates the need for this type of intervention: the three major challenges for people living with psychosis identified by this survey were financial security, social exclusion and lack of employment. Three quarters of all people living with psychosis earn less than half the national estimated disposable income, and labour force non-participation is over 70%, while over 60% of people report difficulties in establishing and maintaining relationships[1]. These issues are closely interrelated, and innovative, evidence-based interventions exist to address them, which have their greatest potential benefit when they are offered early in the course of illness, before disability becomes entrenched. Specific programmes to address deficits in social cognition enhance these young peoples' ability to participate in society[10], while support to remain in education or training is crucial to enable them to attain their vocational goals. There is a sound

evidence base for the effectiveness of supported employment, particularly with the individual placement and support model, and this model can also be applied to education and training[11]. Early data from EPPIC suggests that this approach is effective with those experiencing a first episode of psychosis, and because these young people are less likely to already be dependent on disability support they are more inclined to actively seek further training and employment[12]. Unfortunately, these interventions are not as widely implemented in Australia as they should be, and there is considerable scope for service enhancement in this crucial area.

An extended tenure of care is necessary, at least for the approximately 20% of patients who make an incomplete recovery from their first episode, many of whom can be identified as being in need of longer-term care within their first year of treatment, as well as those who are discharged at the end of their current two-year tenure of care but are still in need of specialist interventions. Increasing evidence suggests that the gains of specialised early intervention programmes can be eroded if young people with ongoing difficulties are discharged too early, and that these gains can be maintained if they are offered up to five years of care within a specialist early intervention setting. These extended care models could be offered in a stepped manner, with less intensive support being necessary after the first two years of care, but with access to the components of the early intervention model deemed clinically necessary being determined on an individual basis for each young person. Early data from a Canadian study indicate that a stepped care system involving two years in an early intervention service, followed by three years of stepped-down care at a level determined by the patient's individual clinical needs, gives better outcomes for young people and prevents any deterioration in the gains made during the first two years of treatment[13].

We believe that the NDIS has a role to play in early intervention for Australians experiencing a first episode of mental illness by offering these young people specific supports to allow them to address their psychosocial and functional recovery needs, over a guaranteed extended tenure of care if necessary. This could take the form of an individual allowance to the young person, to be used to enable them to access specific recovery programmes or supports including housing, or dedicated funding to facilitate the implementation of functional recovery programmes within early intervention services nation-wide. Such programmes have been shown to significantly enhance recovery, as well as reduce social isolation and the impact of a severe mental illness, and to a large extent are not supported under the current funding arrangements. These programmes will require adequate resourcing with specialist staff, both clinical and non-clinical, and should include vocational consultants and education liaison officers within all early intervention services to work with each young person to support them in attaining and maintaining in their recovery, and reaching their educational or vocational goals.

For further information, please contact Christian Smyth

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