5 April 2013

mhcc
mental health coordinating council

PO Box 668 Rozelle NSW 2039
T 02 9555 8388
F 02 9810 8145
E info@mhcc.com.au
W www.mhcc.org.au
ABN 59 279 168 647

The Hon Jenny Macklin MP

Minister for Families, Community Services and Indigenous Affairs
Minister for Disability Reform
Parliament House
Canberra ACT 2600

Dear Minister

Subject: Early intervention and the National Disability Insurance Scheme

The Mental Health Coordinating Council (MHCC) is the peak body representing mental health community managed organisations (CMOs) in NSW. Our members provide a range of psychosocial support and clinical services, advocacy, education, training and information services with a focus on recovery orientated practice. MHCC's membership consists of over 200 organisations whose business or activity is wholly or in part related to the promotion and/or delivery of services for the wellbeing and recovery of people affected by mental health conditions. We work in partnership with both State and Commonwealth Governments and participate extensively in policy and sector development and facilitate linkages between government, community and private sectors in order to affect systemic change. MHCC also manage and conduct research projects and develop collaborative projects on behalf of the sector. MHCC is also a registered training organisation (MHCC LD) delivering nationally accredited mental health training and professional development to the workforce.

MHCC is a member of Community Mental Health Australia (CMHA) a coalition of the eight state and territory peak community mental health organisations representing over 800 CMOs. CMHA was established to promote the benefits of community support services in improving outcomes for people with psychosocial disability and reducing the need for hospital admissions.

MHCC write to you following the publication of the draft NDIS Rules released 5 March 2013. In this letter we focus particularly on the issue of early intervention (EI) for people with mental health conditions currently accessing a number of block funded community programs including Day to Day Living (D2DL), PHAMs, and state level programs such as Boarding House reform programs.

Under the NDIS Rules, EI for people with psychosocial disability has been ruled out (Support for Participants 7.8(b)) and deemed to be the responsibility of health services.

We are concerned that people currently supported by community programs which perform the function of keeping people out of hospital, by supporting social inclusion, activities of daily living and tenancy and employment support will be ineligible and unable to access these EI supports when the NDIS is implemented.

Health services do not provide EI programs for the same group of people currently supported by PHaMS, D2DL and other community support services. Health focuses its EI programs on youth programs, first episode psychosis and ante and peri natal initiatives. It

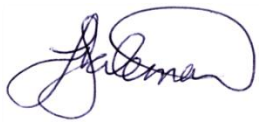
provides very little for adults requiring supports to stay well in the community. In NSW the Ageing Disability and Home Care agency (ADHC) funds some supports in this regard particularly for people with complex needs such as those living in Boarding Houses. It wasn't until the Commonwealth funded the PHaMS, D2DL, respite and other community based initiatives that EI for adults with psychosocial disability was more adequately addressed.

We ask that the NDIS Rules reflect that psychosocial support services are recognised as early intervention and come under scope of the NDIS. By doing so, the positive outcomes for consumers and their families achieved by these programs, keeping people well in the community, will be maintained.

We attach a number of consumer stories known to us that illustrate the problems for people who should be considered as eligible from the perspective of early intervention across the age range.

MHCC are happy to discuss these matters with you in more detail and would welcome an opportunity to present our position in more detail. We thank you for your interest and look forward to hearing from you in the near future.

Kind regards



Jenna Bateman
Chief Executive Officer
Mental Health Coordinating Council

cc. Minister Mark Butler
Commissioner Alan Fels
Commissioner John Feneley
Minister Kevin Humphries

Consumer stories – based on examples of NSW consumers known to MHCC, de-identified and shared with Mental Health Council Australia

John is a 25 year old man with a history of anxiety and depression. Leaving home at 14 due to domestic violence he stayed temporarily with friends. He has remained homeless and living on the streets for 6 years.

At 20 he received support from a youth refuge and was assisted by a youth worker to find part-time employment. Subsequently John found stable accommodation and was in a committed relationship.

However, six months ago, John's partner of 3 years died by suicide. He gave up work and now spends much of his time walking the streets, watching TV and smoking cannabis. John is at risk of losing his accommodation due to non-payment of his rent.

John recently began attending a drop in centre for young people and connected with the Personal Helpers and Mentors (PHAMs) program. The PHAMS worker assisting him has referred him to grief counselling and has provided a referral to the Tenants' Union (information and advocacy service). Through this referral John was able to negotiate a debt arrangement with the Department of Housing. John is now also connected to a tenancy support service that is supporting him to sustain his tenancy.

Support for John would be considered EI and from our current understanding of the NDIS eligibility criteria, he would not be eligible. The vital support he currently receives from PHAMs may no longer be available should EI be considered only the responsibility of Health. Without community support John's mental health is likely to deteriorate.

Justin is a 20 year old university student who experienced first episode psychosis after a weekend party where he took a number a drugs including ice, together with alcohol. Subsequently diagnosed with Bipolar Affective Disorder, he is experiencing difficulty with his treatment plan - mainly the side effects of Lithium. He reports that he has gained 10 kilos, has poor concentration, feels drowsy and has difficulty continuing his studies. He also reports muscle weakness and has developed bad acne as compounding issues as to why he is reluctant to take his medication.

The situation is causing family friction as Justin fluctuates between chronic depression and less frequent episodes of mania, exacerbated by his use of cannabis when depressed. Having once or twice stolen from his parents and taken their car without permission Justin's parents are beside themselves with worry and are not coping at all. Justin desperately wants to leave home and continue his studies online for a while.

Justin would clearly benefit from proactive support to ensure that his treatment plan is managed holistically to encompass his mental and physical health needs together with monitoring medication. This will require building a relationship with a support worker in whom he trusts and can build rapport.

If Justin's condition remains unstable it is likely that he may be hospitalised, and if insufficiently supported thereafter may become severely disabled by his illness and require disability supports through the NDIS.

Justin's potential eligibility under the NDIS is unclear. Early intervention should be supported in order to minimise the risk of Justin becoming a long-term recipient of acute and NDIS services in the future. Justin is currently well supported by a PHAMs peer worker who is assisting Justin to meet his recovery goals and assisting Justin negotiate a treatment plan with his psychiatrist.

With PHAMS resources coming under the NDIS it is unclear what kind of support Justin will be eligible for support under the NDIS or any other system.

Chris, aged 30, was given a diagnosis of schizophrenia at age 19. He was a heavy marijuana user at the time, and the psychosis was suspected to be drug induced. Chris's treatment plan was managed by public community mental health services for about six years. For two years Chris was on a CTO and received a disability support pension. However, about four years ago Chris decided to give up marijuana, and with the support of his treating psychiatrist his medication was reduced and eventually ceased. Determined never to go back on medication the treating team assessed that Chris no longer required assertive treatment allowed the CTO to lapse and therefore Chris no longer had any obligations under the law to engage with services.

A year before the CTO ended, Chris was employed to work from home by a family member who owned a software business interstate. He lives with his parents in a small three bedroom home working from his bedroom. A year later, the business was sold and Chris was retained by the new company.

At first glance it would seem that this story has a happy ending for Chris, no longer on medication, has a job, somewhere to live and does not use mental health services.

However, Chris' parents report that over the two years since the CTO lapsed Chris became more reclusive, mostly stayed in his bedroom and when leaving his room needed to close the curtains.

Chris's parents contacted mental health services about two years after he ceased treatment, as they were extremely concerned. The crisis team were called and Chris was referred back to his original case manager Steve.

Steve contacted Chris by phone once and was told that he was well and unwilling to engage with mental health services. Steve encouraged Chris to visit the mental health service but was unsuccessful. However Chris is willing to have a PHAMs worker visit.

Chris attends to his own ADLs but Chris's parents are concerned about the sustainability of Chris's employment as he isolates and is increasingly reluctant to engage where necessary outside of the house to meet his employer's needs.

Without access to any PHAMs or similar program Chris will likely deteriorate especially if his parents are no longer there to support him.

Without and EI package Chris is unlikely to engage with any service and is likely to end up being involuntarily detained if he becomes more unwell.