

The peak organisation representing the non-government mental health sector in Tasmania at a state and national level

## **Submission**

## Disability Care and Support: **Productivity**



The Mental Health
Council of Tasmania has
a vision for a vibrant and
effective mental health
sector in Tasmania.

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## Submission

The Mental Health Council of Tasmania (MHCT) is the peak body representing the interests of consumer, carer and community mental health sector organisations in our state. We provide a public voice for people affected by mental illness and represent and serve the organisations in the community sector that work with them.

The MHCT advocates for effective public policy on mental health for the benefit of the Tasmanian community as a whole and has a strong commitment to participating in processes that contribute to the effective provision of mental health services in Tasmania.

The MHCT appreciates the opportunity to provide comments on the Consultation Paper for the Disability Care and Support proposal presented very thoroughly in two volumes by the Productivity Commission.

We would like to start by stating that we share some of the concerns of our colleagues at the Mental Health Community Coalition in the ACT. The draft report on Disability Care and Support seems to reflect a less than perfect understanding on the part of the Commissioners about the concept of psychosocial disability. One of the implications of the draft report is that mental health services (including community sector services) sit, for the most part, within the medical system and are thought to be delivered primarily by "medical professionals" working in state health departments or in private psychology and psychiatry practices. According to the funding model for the NDIS outlined in the draft report, this assumption, which is not based in fact, suggests that it would be inappropriate for mental health services to be delivered through the NDIS.

As the peak body representing community sector mental health service providers in Tasmania, we cannot overstate the importance of the role that the community sector plays in working with people with serious psycho-social disability. While it is true that a number of Tasmanians with a disabling (corefunction impairing) mental health condition are treated in Statewide and Mental Health Services-funded long-term settings such as Tyenna Blue and Green (which together provide 18 beds in high-dependency settings), it is also true that most community sector supported accommodation providers, peer-support providers and other rehabilitation services are delivered by the community sector organisations that make-up our membership. We are concerned, then, about the future funding (block funding) of these essential services if the NDIS becomes the dominant distributing

mechanism for money targeting people who are seriously disabled by a severe mental illness. If, as the report flags, the NDIS is funded partly by money recycled back through state treasuries but is built around a model that does not adequately recognise the extent of work being done by the community sector, it seems possible that our member organisations could be placed under serious pressure. For the most part, their funding comes from the Tasmanian and Australian Governments. If money was taken away from DHHS, for example, and not replaced under the NDIS (either in block funding or in adequate recognition/accreditation of their current clients and subsequent personalised funding) we could see egregious impacts on the viability of core organisations and also, by extension, the recovery trajectories of a large number of people struggling to the get the most out of an already over-stretched system.

To give just one example of how this might work; one of our member organisations helps over 100 Tasmanians each week improve and enhance their mental well-being through the rediscovery of hope, purpose in life and connection with the community. Many of this organisation's clients may not have a core-limitation that would qualify them for NDIS funding but many can "... be expected to require very costly disability supports" and "... have significant difficulties with mobility, self-care and/or communication" (Draft Recommendations 45). If these individuals were to slip between the NDIS gaps because of classificatory rigidity and the DHHS was defunded to sustain the NDIS, serious problems could emerge. If DHHS was unable to provide block funding to the community sector organisations that look after these cases, both the treatment of the individuals and the future of the organisations that work with them could be jeopardised. Even so, a number of our organisations have indicated that they support patient centred funding in spite of the risks it poses for their own financial security. This is a view held by some but by no means all of our member organisations.

The admission in the Draft Report that the Commission is aware that "the mental health system is under review and this may affect the appropriate system for providing supports", does not inspire a lot of confidence. Our overall sense is that people with disabilities resulting from mental health issues are not given adequate consideration in the draft report. For instance, the report states that:

The boundaries between the mental health sector and the NDIS are blurred for the most severe and enduring mental illnesses. People with these illnesses will sometimes need daily supports that are akin to those of people with a disability more generally. (Disability Care and Support: 22)

We object here to the idea that non-mental health disability is presented as the normative or default disability — mental health disability is not akin to disability it is disability, substantively real in its own right

— while disability resulting from a mental illness is made a secondary or derivative form. This is made all the more striking by the figure in section 1.4 that states that 40% of people with a profound core activity limitation have a mental or behavioural limitation. Given that no other category is supplied into which people with a mental illness could be included, we must assume that they contribute to this 40% and thus may actually make up a large proportion of people with severe (core limitation) disability. If, as the Draft Report forecasts, 360,000 people are expected to be eligible for payments under the NDIS (figure 3.1) and 150,000 people with a mental illness had a core limitation (figure 3.25) — the maths suggests that people disabled by a mental illness will make up almost half of the people eligible for coverage under the NDIS. This cohort is surely large enough to warrant an equal rhetorical and administrative status in the report and makes the seven pages dedicated to their position within the process look inadequate. We need to ask as well, why so much rigorous research was done into topics like hypothecation and litigation, while the thinking work on mental illness and disability has been farmed out to relatively underfunded organisations like our own in the form of a series of open questions within the text of the report. Once again, the impression is that the relationship between mental illness and disability is being put in the too-hard-basket for reasons that remain unclear to us.

Indeed, if State Governments will be asked to hand back health money to the Australian Government as part of the hypothecation process and the NDIS hasn't adequately accounted for mental health costs, the whole community mental health sector could face a funding crisis. It is our opinion that there should be no boundaries built to sequester mental health disability from physical disability as long as the former meets the criteria for core function limitation (or any equivalent thereof). As long as this is the case — and much rests on the sophistication of the assessment toolbox and all the classificatory frameworks that are built into the scheme — mental health consumers with a corefunction disability should be given funding to buy services from the community sector organisation that best meets their needs according to a bureaucratic logic more or less identical to the one that applies in the case of physical disability.

A core-function disability that derives from a mental health condition could be caused by a range of illnesses, and we are concerned that only schizophrenia and 'psychosis' are 'named-up' in Table 14.1 Parameters used to proxy the number of people in tier 3. Research now shows that a whole range of mental illnesses have the potential to be disabling. Bipolar affective disorder, for example, is as serious a mental illness as schizophrenia and has a burden of disease rank in the 80<sup>th</sup> percentile which makes it more vicious than nearly all purely physical ailments — ailments, it needs to be said, that our society seems to find much easier to understand and accept (and to respect in terms of meaningful and innocent suffering) than severe mental illness. Bipolar also has a suicide rate of 10-18 percent of sufferers mainly depending on the frequency of deep depression and the effectiveness of treatment. Even if, bi-polar affective disorder is core-function inhibiting only in its psychotic (depressive or manic)

mode, its seriousness when compared to schizophrenia should not be underplayed and can certainly cause situations in which the sufferer is extremely limited in her or his capacity to achieve self-care, mobility or communication competence.

The proposition in the Draft Report that the Commission is seeking feedback on where the boundaries should be drawn between mental and physical disability (as if they could or should be finally drawn, both clinically or philosophically, when most of us are materialists now and do not believe in Descartes' res cogitans or one of its modern metastases — which is to say, that we only thought these illnesses were in the mind before we were able to replace the mind with the brain and find objective correlatives for every thought and feeling, no matter how confused or bizarre, in the electro-chemical communications that take place inside our skulls. However, we approach it, The implications for the NDIC's costs, eligibility conditions, service offerings and integration with the mental health sector" (Overview), do not inspire a lot of confidence that mental health has been considered an equal partner to physical disability in the preparation of the Draft Report.

We understand that the Productivity Commission is concerned about the cost of including people living with mental illness in the NDIS. This may have led to a resistance to accepting the full magnitude of the mental illness/disability problem in this country. In this regard, we draw the Commission's attention to the fact that mental illness causes more lost years of productivity than any other form of disability. The long quote below is worth including in full because it presents a credible and thorough description of how severe mental illness can be profoundly disabling and extremely intrusive over the course of a consumer's life:

The cost of managing one patient with schizophrenia per year is \$24,000 per episode, with a minimum of one inpatient hospitalization episode [6]. There are approximately 220,000 (1% of the Australian population) suffering from schizophrenia). An estimated 150,000 patients fall into the category of needing one inpatient hospitalization per year. [7] This is a direct cost of \$3.6 billion for patient care per year for just this group. With new treatments and increasing efficiency of care delivery, we estimate at least 2.5% reduction in hospitalization which is \$90 million saving on direct costs per year. With respect

<sup>&</sup>lt;The <u>Burden of Disease and Injury in Australia</u> study indicated that mental disorders constitute the leading cause of disability burden in Australia, accounting for an estimated 24% of the total years lost due to disability. <a href="http://www.aihw.gov.au/mental-health/">http://www.aihw.gov.au/mental-health/</a>, viewed 18 April 2011.

to disability pensions, 60 billion dollars per year is spent in Australia. 28% of this or 16.8 billion dollars per is spent on people with mental illness [8].

A 2.5% reduction of this disability pension due to new treatments would be a saving of \$420 million per year. Indirect costs with carer loss of productivity is more difficult to estimate, but if we assume each person with persistent schizophrenia (assume this to be 50,000 Australians) [9,10] needs a minimum of one full time carer –this is approximately \$60,000 per individual in either salary of professional carer or lost salary in the case of a family member. This is \$3 billion per year in addition to the hospitalization costs described above. New treatments with a 2.5% assumed reduction in carer cost is a saving of \$75 million per year. These estimates are conservative and do not take into other indirect costs such as a return of dollars to the community in the form of taxes paid by productively working patients and carers.<sup>2</sup>

Our concerns here, of course, do not disqualify our in-principal support for the NDIS, especially given that it aims to hypothecate funding in the order of double the existing state expenditure. To put it in plain language, any new money for health or welfare is welcome in the broadest terms and it would have to be horribly misspent to be sapped of its all its positive energies, at least, from the social justice position that we take. We are also encouraged by the offer of an olive branch to a sector that is traditionally low-wage, low-status and whose clients have had to make-do with inadequate support and sometimes substantial deprivation and its pursuant unhappiness. We agree that many disabilities are 'socially' constructed and that some of the disadvantage that seems so 'intrinsic' to a given condition can often be mitigated by inexpensive psycho-social and environmental interventions such as wheel chairs and supported accommodation.

We do anticipate though that state health departments will have a range of issues to do with the scope, division of powers, etc implications of the proposal but do not feel that it is within our remit to speculate in detail about how these concerns might look.

We are also interested in how the user-centred funding model so central to the NDIS will work alongside the plan to implement flexible care packages that we commented on in a submission

<sup>&</sup>lt;sup>2</sup> < Professor J Kulkarni, 'The Cost Of Mental Illness, Director, Monash Alfred Psychiatry research centre (MAPRc)', p. 4.> viewed 18 April 2010.

to the Director, Community Services Section, Mental Health and Suicide Prevention Programs Branch, Department of Health and Ageing in February of this year. It was stated in the Flexible Care Packages For People with Severe Mental Illness document that:

Under the NHHN Agreement, the Australian Government will take full funding and policy responsibility for primary mental health care services for common disorders such as anxiety and depression or mild to moderate severity, including those currently provided by states and territories.<sup>3</sup>

In the NDIS, of course, this is exactly what is being done. We are also aware that the scale of the two reforms (\$60 million for the FCPs and \$6.3 billion for the NDIS) makes comparisons difficult and given that both proposals should carve out a greater role (and commensurable increases in funding) for community sector mental health organisations (our principal memberships) we are not discouraged by the contours of this new policy landscape. Again, though, our concerns about core funding being withdrawn from community sector mental health care organisations that were identified in earlier submission, remains in place.

We still think that provision needs to be made for stable core-funding to community sector mental health organisations so that these organisations cannot be endangered by short-sighted, ill-advised or knee-jerk consumer spending. The role of the service provider or DSO in the proposed NDIS appears to be one of the keys to safeguarding the full range of service options in the NGO sector and we are encouraged that room exists in the plan for a negotiated compromise between person-centred approaches and service-centred (block funding) approaches.

We recognise the problematic way that block funding can lead to decisions being made about the service-user without the service-user's consent. But we can also see how "the wholesale replacement of block funding with direct consumer choice and payment of suppliers would generate high levels of revenue uncertainty and would result in unmanageable volatility in demand" (8.43). Within the Mental Health sector, of course, this looks like a continuation of deinstitutionalisation (or in education – of integration and inclusion) which some clinical professionals, service-users and members of the broader community are still uncomfortable with. We still have some reservations whether the best theoretical position — in an ethical sense rather than a practical or deliverable one — is being pushed through, even when it might not necessarily produce the best results on the ground. We do, of course, see some merit in the report's suggestion that the service providers will be required to adapt and adjust and make themselves

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<sup>&</sup>lt;sup>3</sup> Flexible Care Packages For People with Severe Mental Illness: The Access to Allied Psychological Services Component of the Better Outcomes in Mental Health Care Program, January 2011, p. 3.

attractive to the service users. If the onus of 'competency and rationality' is claimed by the service provider then it seems appropriate that *it* should adjust to the 'irrational, unwell, symptomatic' consumer rather than vice versa.

It appears that Figure 6.1 demonstrates that this is an intended outcome of the reform. We want to be clear, even so, that we fundamentally agree with the statement in chapter 6 of the draft report which contends that:

People should be given much greater power and choice in a new system, with the objective of giving people greater flexibility and control over their lives – with the ultimate goal being greater wellbeing. Consumer choice is one aspect of power (Who Has the Power 6.1).

And we are encouraged further by the countervailing propositions that:

Entirely untied self-directed funding could lead to adverse outcomes for people with disabilities, would fail to meet the usual public accountability standards for public monies, and could risk discrediting self-directed funding generally. (Who Has the Power? 6.2).

And as paraphrased in section 6.35:

A lot of people with disabilities and families are coming from a background of being disadvantaged, poor, powerless, not used to actually making those decisions. So to expect that people might just jump into a system is, I think, a bit silly. There has to be some of these capacity-building things in place.

Here, as in most things, moderation and compromise seem appropriate and we are satisfied that the Productivity Commission has taken reasonable account of these risks. Even so, the overall bias of the proposed scheme to 'physical' disability is reflected in a lack of detail about how people with a 'severe' disabling mental illness like schizophrenia or bi-polar affective disorder might struggle to manage their funding packages in a 'rational' manner – and we use that loaded term deliberately to emphasise the realities of mental illness as well as the perception of mental illness that still exists in the community and among the full range of service providers.

Rational choice theory of course is at the base of many attempts to put the health service user in charge of their funding as well as driving much recent economistic, neo-liberal, competition-biased social thinking. Rational choice theory, of course, tends to ignore the emotional aspects of the decision to purchase as well as shortening the timeframe for determining the value of the purchase. Our experience is that there are some people with severe mental health issues who because of psychosis or other impediments to 'reasonable' action will not be able to act 'rationally' with long term goals in mind or who will struggle to put aside objections to a service that are heavily influenced by muddled or conflicted emotions (sometimes transferential issues in psychotherapeutic language). Here, the role of an intermediary (DSO) will really be put to the test. Service providers too might find themselves allocating valuable resources to keeping a client 'happy' even when they are not at fault and it is the client who is episodic or affectively conflicted or confused.

These concerns notwithstanding, we thank the Commissioners for providing us with the opportunity to respond to the Draft Report. The MHCT will watch in interest to see how the development of the NDIS proceeds and hopes that our comments here are taken seriously. We have listed our major misgivings in detail above, but to summarise; we are concerned that mental illness has not been given a place at the heart of the policy process. We are concerned about the future of our member organisations if block funding is withdrawn from state health departments and from Australian government agencies (even if some of those organisations are not opposed to patient centred-funding). And finally, we are interested in how the 'irrationality' or temporary, episodic lack of judgement that can come with mania or psychosis for people with a mental illness might be balanced against retrograde paternalism in the nation-wide architecture of a practicable client-centred funding model.