FURTHER UNRAVELLING PSYCHOSOCIAL DISABILITY:

Experiences from the NSW Hunter Disability Insurance Scheme Trial Site[1]

18 months into the NSW trial …
July to December 2014

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We are now at the 18 month mark for activity related to mental health and psychosocial disability within the NSW NDIS trial site. This is the half-way point in the three year trial and much learning has occurred for us as a result of the important partnership between MHCC and the NSW Mental Health Commission.

This last 18 months has gone very quickly and it won't be long now until we begin to see the roll-out of the full Scheme across NSW commencing July 2016 and scheduled for completion June 2018. The program for this to occur has still not been established but the NSW government is to present a plan to COAG by June this year.

The parallel processes of NDIS implementation and the NSW Health 'Partnerships for Health' NGO grant reform need to be brought into greater alignment to achieve the aspirations of the whole-of-government NSW Mental Health Strategic Plan.

Reflections on the First 18 Months of the NDIS in NSW

During the first 18 months of NDIS design and implementation in the NSW Hunter trial site, much has been learnt about the eligibility and access of people with high levels of psychosocial disability related to a mental health condition. We are now in a much better position to review and consider the implications for the future of the NDIS, for our sector and as well as for people who may be participants in the NDIS or those considered ineligible for Tier 3 funded services and supports.

The NDIA quarterly report released in December tells us that at the end of September 2014, 622 people with a diagnosis of schizophrenia or another condition resulting in psychosocial disability related to a mental health condition had accessed the NDIS nationally. This figure includes 238 people in NSW (38%; an increase of 79 people since the end of June). While these numbers are substantial for the purposes of facilitating learning, people with psychosocial disability represent less than 1% of all people accessing the NDIS nationally. These numbers are also less than 1% of the estimated number of Australians living with mental health conditions anticipated to be accessing the NDIS both in NSW and nationally at full roll-out (i.e., 19K and 57K respectively).

While the NDIA quarterly reports are welcome, they are insufficiently detailed to maximise learning about the NDIS and mental health/psychosocial disability. For example, the quarterly reports tell us nothing about the number of people living with mental illness applying for an NDIS service that are found ineligible. MHCC has been informed that some 35-40 people with psychosocial disability in the Hunter trial site that applied for NDIS Tier 3 services in 2013/14 were declined. These people's circumstances are currently under review by NDIA.

We are now aware that the impact of the NDIS on consumers, carers and the resources of existing service providers is very high. With regard to the later, we know that greater efficiencies in coordinated and integrated health and disability/social care service delivery are yet to be identified and look forward to this continued learning.

It is of concern that some potential and successful NDIS participants, and their families and carers, are becoming emotionally and psychologically distressed

[1] The title of this article acknowledges the very important foundational work undertaken by the National Mental Health Consumer and Carer Forum in their 2011 publication *'Unravelling Psychosocial Disability'*.

Mental Health Commission of New South Wales
mhcc mental health coordinating council

as a result of their access experiences. This indicates a need for more recovery-oriented and trauma-informed service delivery approaches by the NDIS.

A key event in the first 18 months has been the appointment in April of Eddie Bartnik, the former WA Mental Health Commissioner, as an independent national Strategic Adviser to the NDIA on mental health, local area coordination and community capacity building. Eddie has recently been exploring the experiences of the NSW Hunter trial site, especially as this relates to mental health/ psychosocial disability.

Highlights of the Last Six Months

A comprehensive report on the NSW 2013/14 experience of the NDIS from a community-based mental health sector perspective has now been completed. The report captures much of the learning to date and makes suggestions for priority actions and activities to take our work forward.

With the commencement of the year 2 trial sites in July, we have seen opportunities for additional NDIS mental health/psychosocial disability activity in all states and territories except Queensland. This is critical to both learning and scaling up a shared understanding of the framework for psychosocial disability within the NDIS.

In August, the Mental Health Services (TheMHS) Conference convened a featured symposium exploring the NDIS and mental health. It was facilitated by Pam Rutledge, CEO at RichmondPRA, and includes presentations by NDIA, MHCC (on the NSW experience), the Western Australia Association of Mental Health and Mental Health Australia. The symposium is available as a webcast and can be viewed here: https://mhaustralia.org/general/ndis-how-mental-health-fairing.

In October, MHCC presented in a National Respite Association Conference stream that focused on mental health respite issues and the NDIS. The situation for family and carer support services under the National Disability Strategy, including but not limited to the NDIS, continues to lack clarity. MHCC learned that the mental health sector is lagging behind the disability and aged care sectors in regard to shaping the future for family and carer support services. This must change.

In December, MHCC presented to the NSW Ministry of Health Mental Health Program Council on our experiences in and learning from the NDIS trial site. Communities across NSW are encouraged to begin identifying and collecting the functional assessment information required to support people's access to the NDIS (ie, in addition to diagnostic assessment information which, while helpful, is not actually a requirement for access).

Recent Activity of the Hunter NDIS and Mental Health COP Forum

At the end of December the COP Forum had 290 participants in total with about 70 people attending each event. A breakdown of forum participation is below:

- *118 community sector workers from the trial site*
- *70 community sector workers from outside the trial site*
- *64 other people from the trial site*
- *35 other people from outside the trial site*
- *3 consumers.*

At the September Hunter NDIS and Mental Health 'Community of Practice' (COP) Forum we heard more stories from the NDIA, Hunter New England Mental Health Services (HNEMHS) and Partners in Recovery (PIR) about people's access to and experience of the NDIS. The NSW Ombudsman's Office also presented on their enhanced roles and functions under the new Disability Inclusion Bill 2014 (NSW). The Ombudsman is keen to hear from people with mental health conditions and service providers in the Hunter with lived experience of the NDIS.

At our fourth and final event for 2014 in December, we focused on what Tier 2 NDIS services might look like. NDIS Tier 2 services aim to:

- Provide information, linkages and capacity building
- Better link individuals to mainstream supports
- Assist services to be more inclusive and responsive to the needs of people with disability
- Direct investment towards evidence based interventions that improve outcomes for the individual.

We were delighted that Eddie Bartnik joined us for this discussion, along with Ability Links and PIR. Ability Links is a new NSW initiative created to support the ongoing reforms of the disability service system in NSW, including NDIS Tier 2 design and implementation.

PIR is a new Commonwealth initiative that is 70% 'in-scope' for NDIS.[2] It aims to support people with severe and persistent mental illness with complex needs, and their carers and families, by bringing together multiple sectors, services and supports that may need to work in a more collaborative, coordinated and integrated way. PIR provides time-limited service coordination and has a role in closing local service 'gaps'.

We discussed how NSW Health funded community sector mental health programs, none of which are 'in-scope' for the NDIS, will be an important part of Tier 2 of the NDIS. This means that there are important discussions that need to occur about how the NSW Health *'Partnerships for Health'* NGO grants reform might contribute to the operationalization of the NDIS and in establishing benchmarks for access to Tiers 3 and 2.

Eddie shared with us the recent establishment of an NDIA Mental Health Expert Reference Group and two related national projects to explore: 1) eligibility and access; and, 2) supports and pricing. The projects will help to inform future mental health related data collections.

HNELHD Structures for NDIS Design and Implementation

In 2013, MHCC attended a fortnightly Hunter New England Local Health District (HNELHD) and NDIA *'NDIS Health Working Group'*. This was a valuable forum for monitoring and exploring NDIS implementation and the very important and evolving health/disability interface. These meetings included discussions about mental health services.

In 2014, a maturation of the operational and governance structures has occurred including establishment of an *'NDIS Operational Working Group'* with reporting *'Subject Groups'* established for:

- physical health
- children and adolescents, and
- mental health.

A range of structures are emerging within HNEMHS to facilitate their NDIS work. For example, they have identified NDIS 'champions' across the hospital and community based teams who work to identify people potentially eligible for Tier 3 funded services and supports. The 'champions' meet to share their learning with one another, and other interested people. The 'caseload audit' focus is important as many people with high levels of psychosocial disability related to a mental health condition are known to the HNEMHS.

HNEMHS have benchmarked the considerable time and costs associated with supporting a person to access the NDIS. Impacts are high because of the NDIS requirement for informational about impairment and functioning. A concern is that when people are being supported by public mental health services to access the NDIS there is an impact on the availability of acute and subacute assessment and treatment services.

The HNEMHS NDIS experiences will inform directions for state wide roll-out of the NDIS from a NSW Ministry of Health perspective.

Moving Forward

MHCC continues to be vigilant to ensure that no one is disadvantaged as a result of NDIS implementation in the NSW trial site.

The needs of people affected by psychosocial disability continue to not be well recognised or understood. The greater systemic inclusion of consumer, carer and community representation and participation across the range of local, state and national NDIS operational and governance structures is critical to achieving this.

We are concerned that not all people needing Tier 3 funded services and supports will be known to public mental health services. MHCC is advocating for population based planning approaches in mental health sector reform. Understanding the gap between those people with mental health conditions known to public mental health services and others not known to them is part of this.

For example, the population of people 18 to 64 years in various parts of the HNEHLHD catchment with severe and persistent mental illness that potentially require mental health treatment and/or psychosocial disability and recovery support services is provided over page.[3]

[2] The term 'in-scope' is still not well understood beyond it being a financial contribution to the NDIS.

[3] This information is derived from and builds upon MHCC's (2013) 'NSW Community Managed Mental Health Sector Benchmarking Project: Final Report' which used the methodology of the National Mental Health Service Planning Framework (both documents remain draft and confidential).

Geographic Area	2011 Census Population	Number of People with Severe Mental Illness	Estimates of people known to HNEMHS
Hunter New England	527,090	9,277	5,367
Hunter	421,907	7,425	4,096
New England	105,131	1,850	1,271
Newcastle LGA	99,762	1,756	1,737
Lake Macquarie LGA	117,338	2,065	1,126
Maitland LGA	49,671	874	637
NDIA trial site (3 LGAs)	266,771	4,695	3,500

Building efficient and effective responses to the unmet needs of people with severe and enduring mental illness requires not only knowledge of the numbers of people who may need a service but also knowledge of existing government and non-government mental health service infrastructure. This knowledge is also critical to design of the NDIS. Without accessible mainstream and other Tier 2 psychosocial rehabilitation and recovery support services the NDIS will not be sustainable.

MHCC estimate that there are 1,195 people that may not be known to HNEMH in the NDIS trial site. This figure increases to 3,910 for the HNELHD population catchment. Similar population planning work needs to occur for NSW.

Strategic Directions for our NDIS Partnership

MHCC and the NSW Mental Health Commission are now calling our NDIS partnership the *NSW NDIS and Mental Health Analysis Partnership Project*. Directions proposed for taking our shared work forward in supporting NSW NDIS design and implementation are:

1. Effective representation and participation of consumers, their families and carers, and mental health service providers in NDIS implementation and evaluation
2. Increased recognition and understanding of the needs of people affected by psychosocial disability
3. Pursue collaborative, recovery-oriented and trauma-informed health and wellbeing approaches to services and supports planning/review processes
4. Research and development analysis of trial site experiences including the collection of comprehensive data
5. Development of strategic directions for NDIS psychosocial disability and recovery support workforce development
6. Influence development of the framework for NDIS quality and safeguard mechanisms in NSW and nationally
7. Contribute to the national discourse regarding the NDIS and mental health.

The actions and activities to achieve these directions are now under consideration and include continuation of the Hunter NDIS and Mental Health COP Forum.

Concluding Remarks

Organisations operating outside of the three LGAs that make up the NSW trial site are urged to consider what the NDIS might mean for them in terms of both organisational readiness and impacts on service delivery.

Pre-planning for the NDIS is highly recommended. This should include the collection of comprehensive information about people's impairments and functioning where there is potential eligibility and access to Tier 3 funded services and supports. Decision making support of people's choices for funded services also needs consideration.

2015 will bring with it many new opportunities for improved access to community-based services and supports for people affected by mental health conditions, and their families and carers. We look forward to continuing to work with you to maximise these!

Feedback from a satisfied Hunter boarding house proprietor ...

"The NDIS has benefited the consumers greatly. They have so much flexibility now with their lives and, of course, choice in who they want in involved in their lives. A lot of great things are happening … for the first time services are asking them "what can we do for you? Now it is the consumers that can go shopping for services and purchase the ones what they want".

Keep Up-to-date

For more information about the NDIS and mental health/psychosocial disability including updates on activity from the Hunter trial site please visit: http://www.mhcc.org.au/policy-advocacy-reform/influence-and-reform/ndis-and-mental-healthpsychosocial-disability.aspx