

FURTHER UNRAVELLING PSYCHOSOCIAL DISABILITY:

**Experiences from the NSW Hunter
National Disability Insurance Scheme
Launch Site¹**

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We have now passed the two year mark for the trial of the National Disability Insurance Scheme (NDIS) in the Hunter. The NDIS was not expected to roll-out in other parts of NSW until July 2016 and MHCC was pleasantly surprised by the government's announcement of an early roll-out for young people under 18 years from July 2015 in Western Sydney (Nepean/Blue Mountains).

This will be an opportunity to further explore issues for young people and early intervention. While young people have been included in NDIS implementation in the Hunter next very little experience of the NDIS by young people with mental health conditions has been identified by MHCC.

However, many families and carers have told us of their experience and they identify that young people can find it difficult to engage with the opportunities presented by the NDIS.

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'.

Reflections on the first two years of the NDIS

The first two years of the NDIS at the NSW trial site in the Hunter has resulted in considerable learning for everyone. MHCC's 'NDIS and Mental Health Analysis Partnership Project', being undertaken in partnership with the NSW Mental Health Commission, has contributed significantly to this learning and especially through establishment of the Hunter NDIS and Mental Health Community of Practice (COP) Forum.

At the end of March 2015, the forum had 317 participants in total with about 70 people attending each event. A breakdown of forum participation across all seven events is below:

- 136 community sector workers from the Hunter
- 75 community sector workers from outside the Hunter
- 77 other people from the Hunter (mostly Hunter New England Mental Health Service staff)
- 26 other people from outside the Hunter
- 3 consumers (and with other consumers and carers participating from within paid peer work roles).

Concern about the low level of systemic consumer and carer engagement in NSW NDIS implementation is being considered with Being (formerly the NSW Consumer Advisory Group), ARAMFI and Mental Health Australia and strategies to remedy this are being considered.

The NDIA reports that at the end of March 2015 there were 1,039 NDIS participants with a primary psychosocial disability nationally and 534 participants with a secondary condition of a psychosocial nature. For people with a primary psychosocial disability, 866 of these had approved plans and 269 of these were in NSW. At the end of 2013/14 170 people in NSW had an approved plan. This indicates a significant deceleration in NDIS access by mental health consumers in NSW during 2014/15. The reasons for this are not yet fully understood or agreed.

MHCC continues to enquire about a group of 35-40 people in the Hunter trial site with mental health conditions who in 2013/14 were denied access to the NDIS. We are informed that review has been undertaken and that all decisions are sound. People with mental health conditions declined access to the

NDIS are encouraged to request a review of their circumstances if they believe a wrong decision has been made. A review request can be made directly to the NDIA and help to do this is available through Disability Advocacy NSW (Ph. 1300 365 085).

MHCC is concerned about issues related to processes and outcomes for Commonwealth funded mental health program clients transitioning to the NDIS and their engagement and access. Community managed organisations are reporting a slow-down of these processes and also less than optimal interactions with the NDIA in determining eligibility and access. Reports of some consumers and carers who have been distressed by these practices is of great concern.

The lack of NSW specific NDIS and mental health engagement, eligibility and access data makes monitoring the quality and quantity of these issues challenging.

MHCC will continue to advocate for the NDIS experiences of people with mental health conditions and those that provide services and support to them to be better understood and to ensure that no-one is disadvantaged as a result of implementation.

Highlights of the last six months

An important highlight of the last six months has been publication of the Hunter Partners in Recovery (PIR) report describing their first year of lived experience of the NDIS: <https://www.hunterpir.com.au/wp-content/uploads/2015/04/Hunter-PIR-and-NDIS-Building-a-Stronger-Partnership.pdf>

The Hunter is unique in that it was the only Year 1 2013/14 adult NDIS trial site which also has a PIR program. The report describes that at the end of December 2014 there were 50 joint NDIS consumers from a total of 229 Hunter PIR clients from the three LGAs that make up the Hunter NDIS trial site. It describes their experience of the NDIS and also key issues that have emerged relating to the:

- category 'coordination of supports'
- recognition of Hunter PIR's innovative sector reform and capacity building contributions, and

- risk of Hunter PIR-eligible people being excluded from the NDIS due to a range of barriers.

Another highlight has been the considerable work undertaken by the NDIA to better understand the NDIS experience of people with mental health conditions. This has been in the form of two national projects that will soon report on their findings and make recommendations for further work to be undertaken:

- Operational access for people with psychosocial disability, and
- Design of individual supports for people with psychosocial disability.

Both projects are benefiting from strong consumer, carer and community representation.

The projects are also informed by collaborative work between the NDIA, NDIS Independent Advisory Council (IAC) and other key stakeholders to finalise and publish two important resource and discussion papers:

- *'Psychosocial Disability and the NDIS: An Introduction to the Concept of Holistic Psychosocial Disability Support'*, by Mr Paul O'Halloran and
- *'Mental Health and the NDIS: A Literature Review'*, commissioned by Mind Australia for the IAC.

Additional information about these activities can be found on the NDIA Mental Health Sector Reference Group website:

www.ndis.gov.au/news/ndia-mental-health-sector-reference-group

MHCC is working closely with Community Mental Health Australia (CMHA) and the NDIA on both these projects. We are also the lead agency for CMHA on a Mental Health Australia NDIS Capacity Building Project exploring community managed mental health sector workforce impacts and making related recommendations.

The NDIS and Mental Health Workforce Project will complement work undertaken by the Commonwealth Department of Social Services to develop a *'NDIS Integrated Market, Sector and Workforce Strategy'*: <https://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/ndis-integrated-market-sector-and-workforce-strategy>

This Strategy will strengthen directions for the NDIS Sector Development Fund that has supported aspects of 'market' capacity building for the past three years.

... to ensure the NDIS meets the needs of participants with mental health issues, it will be necessary to engage the sector to define mental health support roles, related job design and training requirements and establish how these roles differ from, and overlap with, other disability support roles.

(NDIS Integrated Market, Sector and Workforce Strategy, p 21.)

Activity of the Hunter NDIS and Mental Health COP Forum

A further highlight of the last six months has been continuation of the COP Forum. The most recent forum met on 17 March and consulted with people about two national NDIS related policy frameworks that are under development.

1. Quality and Safeguards Framework

The consultation, and consequently MHCC's submission to government, highlighted the importance of enhanced supported decision making practice and also encouraged the inclusion of issues related to involuntary mental health practice including but not limited to seclusion and restraint.

MHCC's submission can be accessed here: http://www.mhcc.org.au/media/55573/ndis_qs_sub_-_30.04.15_v.4_f_.pdf

2. Information, Linkages and Capacity-building (ILC) Framework

This consultation highlighted the considerable work that is ahead of us to fully operationalise what 'Tier 2'/ILC services and supports might look like for people not in receipt of a 'Tier 3' Individual Funded Package. This is particularly the case from a mental health perspective where community based services – both government and non-government, 'clinical'/treatment and 'non-clinical'/recovery support - have been poorly funded and fragmented historically.

A revised ILC Framework is expected by the end of July and national consultations recommend that it:

- Make the interface between ILC and mainstream service responsibility clearer
- Better explain how ILC will support people with mental illness.

Renegotiation of the NDIS Bilateral Agreement between states and the Commonwealth is understood to be inclusive of the ILC Framework recommendations above. For NSW, this may also inform future directions of the forthcoming intergovernmental response to the NSW Governments Living Well: A Strategic Plan for Mental Health 2014—2024 and also Partnerships for Health. These discussions may also have informed review of the NDIS 'Applied Principles' with mainstream services, including health and mental health.

The COP Forum will next meet on 24 July. This event will be an opportunity to consult with the NSW Ombudsman's Office about the experiences of NDIS participants with mental health conditions. All of the functions of the Ombudsman's Office apply in the NDIS launch sites in NSW, including resolving complaints and conducting inquiries.

Targeted consultations with consumers and carers with mental health conditions that are NDIS participants will be held following the forum at RichmondPRA on King.

As we move into 2015/16 consideration needs to be given as to how to further escalate the learning from the Hunter trial site, and especially the learning resulting from the COP Forum activity, across NSW.

Strategic directions for our NDIS partnership

The NSW Mental Health Commission will continue to work with MHCC during 2015/16 to position NSW to benefit from the many opportunities presenting through the NDIS and enable people with mental health conditions to have valued and contributing lives in the community.

Our shared focus in 2015/16 will continue to ensure consumer, carer and community inclusion in NDIS design, implementation and evaluation (ie, in ensuring that 'co-design' principles are applied).

Over the next 12 months we will continue to be vigilant about:

- sharing the learning arising from the Hunter trial site
- understanding the experiences of young people with mental health conditions accessing the NDIS in Nepean, and
- contributing to the preparation of the mental health sector across NSW for full NDIS roll-out from July 2016.

It's not too soon to prepare for the NDIS. Detailed plans for the NSW roll-out should be available in September as the NSW government is expected to report on this to the Council of Australian Governments (COAG) by the end of August.

MHCC urges you to call for this information be made public to assist people with mental health conditions and their supporters to prepare.

Moving forward

As noted throughout this newsletter, MHCC is privileged to be involved in a range of national projects that are now underway to help us all better understand and strengthen the inclusion of people with mental health issues in the NDIS.

A complex mental health related learning environment is resulting from NDIS implementation. Both state and national project activities will ultimately help to shape the opportunities presenting through the NDIS and the practices of the NDIA and those that collaborate with them; including those of mental health recovery treatment, rehabilitation and support services.

Recent changes for the NDIS have included the ongoing 'bundling' of services and supports as being either 'core', 'capacity-building' or 'capital' related. This is allow for greater choice and control by NDIS participants and to also allow for greater flexibility in services and supports accessed.

More recently, an 'efficient price' has been introduced for personal care and community participation. This price has been set higher in the short term to support the sector to transition to the NDIS. The national projects work previously noted means that work is underway to establish an efficient pricing model for

supports specific to addressing the needs of participants living with a psycho-social disability.

Considerably more work will be required to ascertain the true unit price costing associated with the provision of NDIS related psychosocial disability support services. Achieving this will also require a greater understanding of the full range of mental health treatment, rehabilitation and support services and skills and qualifications that a range of workers supporting people with mental health conditions require to deliver them.

Concluding remarks

The United Nations Convention of the Rights of People with Disabilities underpins Australia's NDIS. People with a significant psychosocial disability related to a mental health condition provided with access to the NDIS are getting opportunities – that are sometimes many decades overdue - to live valued and contributing lives in the community.

The experiences of people within the Hunter trial site will be under increasing scrutiny as NSW mental health sector reform and NDIS implementation move to become more integrated. Both the NSW Mental Health Commission and National Mental Health Commission have called for actions for this to occur.

The 2015 National Mental Health Commission review has called on governments to 'urgently clarify the eligibility criteria for access to the NDIS for people with disability arising from mental illness and ensure the provision of current funding into the NDIS allows for a significant Tier 2/ILC system of community supports'.

Keep Up-to-date

For more information about the NDIS and mental health/psychosocial disability including updates on activity from the Hunter launch site please visit:

<http://www.mhcc.org.au/policy-advocacy-reform/influence-and-reform/ndis-and-mental-healthpsychosocial-disability.aspx>.