MINUTES

The Mental Health Coordinating Council and the
Mental Health Commission of NSW present
Hunter NDIS and Mental Health Community of Practice Forum
Tuesday 17th June 2014
10.00am - 1.00pm

Venue - Newcastle Jockey Club, Darling St Broadmeadow NSW 2292

Acknowledgements & Introduction
Sage Greene (nee Telford) - Senior Advisor
Mental Health Commission of NSW

Sage provided and Aboriginal and Torres Straight acknowledgement and also acknowledged the contribution of people with lived experience of mental illness and recovery to sector reform. She noted the contributions of people in the Hunter to the development of the MH Commission's strategic plan which was presented to government in April and is now awaiting endorsement before being publically released.

Update on NSW/Hunter NDIS and Mental Health Activity & Actions Arising from the Last Meeting
Tina Smith - Senior Policy Advisor – Sector Development (NDIS MH Analyst)
Mental Health Coordinating Council

69 people attending this forum and about 50% of them identified as being new to our network. Most people attending were from the community sector. There was an increase in the number of people identifying as being either consumers and/or carers and a decrease in the number of people identifying as being HNEMHS staff.

Evaluation results from the 20 March event were shared:

- There were 70 attendees and 27 feedback forms completed
- 81% of people rated the event as 'very good' to 'excellent'
- Most people feeling 'more informed' about the NDIS
- The length of time and frequency of forum is 'just right'
- The things people most liked were (again):
    - Time & opportunity to share with one another
    - Having NDIA present and be able to respond to any issues arising
- There were suggestions for more time for discussion and for people to be able to send questions in advance of meetings.

Action: MHCC is more than happy to accept any issues to be tabled for discussion in advance of meetings.

Actions that have been completed and/or commenced since the last meeting are:

- MHCC/MHCA to continue to explore ways to enhance individual and systemic participation of consumers, carers and community sector providers in NDIS implementation
- MHCC/MHCA advocacy regarding the negative impact of loss of mobility allowance on boarding house residents (and potentially other participants)
- NDIA and HMH to provide most recent MH 'stats' for eligibility and access at these meetings as an ongoing part of their updates
- Sector to provide comments to MHCA on their recent submission to government

- MHCC to circulate MHCA submission to NDIA with Minutes
- MHCC to circulate MHCA fact sheets for consumers and carers with Minutes
- MHCA update to be closer to the front of the Agenda.

There were no questions or comments about the above matters.

Actions that appear to be outstanding since the last meeting are:

- MHCC/MHCA to seek further information from NDIA on the impacts of boarding house resident transitions including assessment and care planning processes and the participation of existing service providers in these (eg. ALI, BH-HASI).
- NDIA to remind their admin. that use of the web based 'My Access Checker' is not an access requirement
- NDIA to consider the value of an inreach/outreach activity to be held at a MH centre based program (eg, RichmondPRA on King) in order to help consumers and carers to become more informed about and engaged with the NDIS/NDIA and eligibility, access, care planning
- NDIA to provide additional information available in regard to plans for deregulation of pricing.

Further information about these items was made available by the NDIA today (see 'Sharing and Reflecting on Experiences' and 'NDIA Update') and/or through a MHCC follow-up meeting with the NDIA that is occurring tomorrow.

Some recent and/or forthcoming activity related to NDIS and MH issues was considered:

- Monitoring the 'phasing in' to NDIS of PHAMS and D2DL clients
- Consideration of the similarities and differences in people being assessed as eligible or ineligible
- MOU between MHCC and NDS
- MHCC presentations on Hunter trail site experiences:
    - 21/4 Australian College of Mental Health Nurses Primary Mental Health Conference
    - 10/4 MHCA Council of Non-government organisations (CONGO) Meeting
    - Presentation and symposium at 2014 THEMHS Conference (August)
- MHCC/NDS/MHCA Organisational and Workforce NDIS Readiness Forum (29 July – Sydney): http://www.mhcc.org.au/media/45397/ndis-org-readiness-forum.pdf.
- 1 year extension of MHCC and NSW MH Commission NDIS 'MH analysis' partnership (to June 2015).

Some MH related information tabled at the 4 June Commonwealth Community Affairs Legislation Committee budget estimate hearings was presented:

- Concern about 'continuity of care' for C'wealth funded MH clients (eg, PHAMS)
- Mention of the May DSS Hunter meeting with C'wealth funded MH programs (6 providers, PIR & NDIA?)
- National statistics as at 31 March:
    - 531 people with a primary or secondary PSD (<1% of 57K target for roll-out)
    - 298 primary (93 with approved plans per NDIA 3rd quarter report)
    - 233 secondary.

Update from MHCA NDIS Capacity Building Project
Liz Ruck - Senior Policy Officer, Mental Health Council of Australia

MHCA reiterated the many opportunities presenting through the NDIS:

- Maximising choice and control
- Multiple levels of access and support
- Recognition of ongoing non-clinical needs
- Increased funding for community mental health
- A growing and specialised workforce.

Along with these opportunities there are:

- Many unanswered questions
- Limited trial site experiences
- Fundamental policy concerns
- Major implementation challenges
- Encouraging recent developments.

The policy challenges include:

- Conflict between 'permanency of impairment' and recovery principles
- Designing a Tier 2 'system' that:
    - Intervenes early to reduce future need
    - Promotes current best practice
    - Responds to fluctuating and unpredictable needs.
- Commonwealth state/agreements
- Demarcating the role of the NDIS from other systems (eg, for Health/MH and NDIS, we need to better understand role delineations as to what is a 'clinical' and 'non-clinical' service?).

Implementation challenges include:

- Mental health skills and experience within the NDIA
- Getting the assessment process right
- Understanding national lessons from trial site experiences
- Pricing structures
- Engagement and outreach.
- Building tomorrow's workforce
- Maximising the input of carers and other trusted people
- Involving non-government stakeholders in rollout.

Recent developments include:

- NDIA capability review
- Possible delays to rollout timetable
- 'Continuity of care' guarantee?
- Imminent problems in Victoria (with most all state funded community sector MH programs being in-scope for NDIS)
- New focus on mental health within NDIA (this includes Eddie Bartnick, the former WA MH Commissioner, who has commenced with MH related responsibilities).
- MHCA proposal to NDIA (circulated with last Minutes). This essentially proposes to slow down the roll-out of the NDIS for MH consumers in order to undertake activities to maximise learning. Feedback consumers and carers is that they do not want to see the roll-out slowed down.

For more information from MHCA:

- Online information hub www.mhca.org.au

- Regular e-bulletins - Please register! ndis@mhca.org.au
- Fact sheets for consumers and carers
- MHCA position paper
- Proposal to NDIA (as per above)
- Community of practice webinars (TBA).

Next steps for MHCA include:

- Development of a national needs assessment (based on experiences of the first year of the Capacity Building Project; forthcoming national stakeholder forum)
- More support for consumers and carers (national workshops)
- Mapping in-scope MH programs and services in each state
- Quantifying the economic benefits of Tier 2 services
- Developing the following discussion papers:
    - Pricing structures
    - Sustainable roles for carers
    - Supported decision making.

The MHCA NDIS needs assessment is being developed for DSS and NDIA/Eddie Bartnick and will hopefully inform aspects NDIA directions in regard to MH including directions for Tier 2 development. The MHCA NDIA Capacity Building Project has been funded for a further two years.
Other discussion

Sharing and Reflecting on Experiences

Some topics were identified for discussion as follows:

- Commonwealth funded client transitions and continuity of care
- Hunter DSS Meeting
- Boarding house residents/Boarding House HASI
- Access to ADHC funded hoarding and squalor programs.

MHCC has been getting reports of large numbers of people in receipt of Commonwealth funded MH programs being ‘phased’ into the NDIS being assessed by NDIA as ineligible for Tier 3 funded supports. Participants were asked if they knew of anyone who had been disadvantaged through this process? No individual disadvantage was identified. People were asked to continue monitoring for disadvantage and bring such situations to the attention of relevant parties (eg, NDIA in the first instance but also MHCC, NSW MH Commission and/or MHCA as needed).

Section 55 of the NDIS Act was invoked to allow information sharing to support the transitions of Commonwealth funded clients (ie, client consent is not required for information sharing). MHCC clarified there position which is to always seek client informed consent and, where this is not possible, to always document the reasons why.

The Hunter DSS meeting in May was with several staff from about six community sector service providers. It was a positive and informative meeting exploring experiences with the phasing in of Commonwealth clients to date. Relationships between the NDIA and the Commonwealth funded community sector providers are positive.

Boarding house residents have begun transitioning in both Newcastle and Lake Macquarie, and including Riverview Hostel. There have been numerous issues needing to be worked through with regard to people residing in boarding house and the 2013/14 Newcastle experience allowed much of this learning to occur. Some Lake Macquarie boarding house residents have also transitioned early. NDIA has been working with HWNS, as an Active Linking Initiative (ALI) provider to better understand boarding house resident issues. All these experiences have resulted in advocacy

arrangements being put in place for boarding house residents through People With Disabilities (PWD). A 29/5 meeting of PWD, CASA (the coalition of Appropriate Supported Accommodation, Sister Myree Harris) and NCOSS contributed to this outcome. Further discussions about boarding house resident safeguards are continuing.

There seems to be some confusion regarding the NDIS access and eligibility of NSW Health funded Boarding House HASI clients. Some of these people are also ADHC funded ALI clients and some are not. Each person will be assessed individually. The question was asked “Can a BH HASI funded client continue to attend a Health funded community based activity program such as RichmondPRA on King in Newcastle or Kaiyu in Lake Macquarie” (ie, without being NDIA funded for that activity)? The answer appears to be, yes, they can continue to attend. In NSW, Health funded MH programs are not in-scope for NDIS. The NDIS eligibility of NSW Health funded MH program participants will need to continue to be monitored.

NDIA acknowledged access barriers to hoarding and squalor programs as an unintended consequence of NDIS implementation. They are hopeful that these issues may be addressed as directions for Tier 2 services become clearer.

A concern was raised about NDIAs risk assessment and management processes. Is sufficient information being provided to community organisations and workers to ensure safety?
A focus on a person’s ‘choice and control’ is good but what about WH&S?

Actions identified through this discussion and elsewhere in the forum are summarised in ‘Meeting Summary and Next Steps’.

Update from National Disability Insurance Agency (NDIA) Hunter
Suzanne Punshon - Director of Engagement and Funding, NDIA

With regard to plans for pricing deregulation, NDIA have begun to ‘bundle’ - that is, to be more flexible – in regard to the support category line items but not deregulated. They are monitoring use of line items to make sure people are not using supports faster than they have been allocated for. They are very keen to see the Tier 2 rollout progressed to help understand flexibility further.

With regard to the consideration of assessment/eligibility ‘in-reach’, NDIA is not in a position to do this type of activity due to resources. The NDIA/Suzi has recently recruited an Assistant Director of Engagement which will add to capacity to address issues arising.

There was some discussion of the recent visit of the NDIS Senate Select Committee to the Hunter including stories shared by HNEMHS.

Suzi introduced Tim Stork, a NDIA Senior Planner who is now Acting Director Service Delivery (following Tanya Brunning’s departure from the NDIA). Tim spoke further to the DSS meeting in May. He attended the meeting along with the new Hunter Launch Site Manager, Kim Birch, and a national NDIA person. He thought it was positive. Some areas have been identified as areas of improvement for the Subject Matter Expert Reference Group (SMEG). These are monthly NDIA meetings with HNEMHS (previously they were fortnightly). These are ground level discussions about access, eligibility, care planning etc. The meetings are useful and action items regarding systemic issues arising can be taken to the NDIA/HNELHD NDIS Implementation Operational Working Group for consideration. The main outcome of the SMEG is refining processes, eg, making sure that staff who have a MH background and related work experience are going to be the key people working with people with mental illness - where possible. Access decisions are now all being overseen by a person with MH experience to double check on decisions. In repose to questions question, Tim clarified that:

- the NDIA has no designated positions for Aboriginal Torres Strait Islander people or people with a disability, including people with MH issues.
- Discussed ways in which the NDIA assists with supported decision making
- Directions for building the capacity of staff to work with MH issues
- Described regular meeting between the NDIA and PIR (they seem to be working as NDIA 'Local Area Coordinators' in the MH space).

There were also questions about the most recent Hunter NDIA MH eligibility and access data (eg, how many people with MH issues are being found ineligible and why?). The NDIA advised that under direction from there head office they were to no longer provide data other than that made publically available in the NDIS quarterly reports.

Update from Hunter New England Mental Health (HNEMH)
Jodie-Anne Bertoldi, Social Worker, Intermediate Stay Mental Health Unit, HNEMH

Jodi described how 18 months ago she found herself in an NDIS key role within HNEMHS. More recently, a document has been circulated internally toward identifying people known to HNEMHS that may be NDIS eligible. She stated that we need to focus on individual people with needs and not numbers.

Not all people potentially eligible for NDIS with be known to HNEMHS. PIR noted that the people that they are seeing typically have quite high support needs requiring 4-5 hours of support daily for assistance with daily living skills, community access etc. A participant noted that there is some very good information about what constitutes 'reasonable and necessary' support is on the NDIA website and that this will require more discussion in a MH context.

Jodi noted that for HNEMHS staff, the NDIS is a very new way of doing business and that they needed more education about the NDIS. Consensus seems to be approaching that the NDIS is not appropriate for moving people out of acute hospital settings

Jodi promoted a forthcoming HNEMHS event regarding strengthening collaboration with NGO disability support providers to be held at the Mater Hospital on 23/6.

Consumer and Carer Representation and Participation in the NDIS
Dr Peri O'Shea – NSW Consumer Advisory Group (CAG) Mental Health Inc.
Jonathan Harms – ARAFMI NSW

The focus of these presentations was to familiarise participants of the activities of NSW CAG and ARAFMI and to think about how to strengthen both individual and systemic consumer and carer participation in the implementation of the NDIS at the Hunter trial site

Peri presented an overview of the history and vision of NSW CAG (see PPT). CAG is the independent, state-wide organisation for people with a lived experience of mental illness (consumers). They work with consumers to achieve and support systemic change. There are about 76 consumer workers in NSW Health MHS across the state (see CAG consumer Worker Project). She explored the importance of consumer participation in all levels of service planning delivery and evaluation. She described the ways that CAG engages with consumers to support their participation. Peri considered some of the opportunities and challenges presenting for consumers through the NDIS. Opportunities include: more consumer choice; access to alternative therapies; more and better fit services; services that suit your recovery; recognition of psychosocial disability; greater main stream empathy; access to disability funding. Challenges include: only the promise of real choice (ie, no appropriate services that consumers want and choose); the requirement of permanent disability being at odds with recovery; MH continuing to be seen as not a real disability; continuing emphasis on those that are 'deserving' and 'undeserving'; NGOs threatened through

market/funding changes). Peri urged consumers to: insist on NDIS support; get involved in service provision and governance; participate in discussions to reconcile permanent disability with recovery; contribute to awareness that mental illness can disable; support NGOs.

People can connect with CAG in the following ways:

- Ph: 02 9332 0200
- www.nswcag.org.au
- Become a member (open to consumers and carers)
- Join our Network NSW to receive news
- Email: policy@nswcag.org.au
- Facebook: https://www.facebook.com/nswcag
- Twitter: https://twitter.com/NSWCAG or find us using @NSWCAG.

CAG would like to broaden the Consumer Worker Project to include NGOs and alternative therapies. There was some discussion about the need for consumer designated positions in governance processes within the NDIA.

Jonathan explained that ARAFMI stands for the Association of Relatives And Friends of the Mentally Ill. ARAFMI NSW is a community organisation of families' carers and friends of people living with a mental illness which encourages an active membership from among all of the diverse communities of NSW, which is informed by their experiences and provides support, education and advocacy in order to help them effectively fulfil their caring role. Jonathan described some of the advocacy that ARAFMI and their national affiliates have been undertaking in regard to NDIS implementation. Some of his key points are below:

- The NDIS and PIR represent great new opportunities for people affected by mental illness.
- It seems that in some states a lot of state government funding for carers has been identified as 'in scope' for the NDIS (although not for NSW)
- However, it is not clear how this funding can be allocated to the care of carers currently, and this could result in an overall reduction of the amount of carer support available, as carer resources are reallocated to consumer support.
- In particular, ARAFMI are concerned that it seems that there is no clear requirement or provision for a separate assessment of the carers needs. There is even a suggestion that the consumer would assess the carers need for direct support and decide if any should be provided out of their package.
- We are uncomfortable with this as the carer's needs are separate from the consumer's (if not independent). The consumer should not be the de facto assessor/gatekeeper for services to meet the carers needs; nor should they be obliged to fund these services out of resources provided for their own support. Many carers would refuse support provided in such circumstances anyway.
- Further to this, there is a lack of clarity around how people will be assessed for their appropriate level of involvement in decision making, and certainly I know there are concerns about the capacity tests being applied.
- This is important to carers as they would like to be involved in supporting the decision making of their loved one, but event this requires rules for it to be done ethically, to prevent exploitation.
- We are also troubled by the idea that if a person is assessed as lacking capacity, then a substitute is simply appointed to make decisions for them.
- There need to be strong guidelines about listening to consumers preferences and even to carers for background information if a substituted decisions maker (either carer or professional) is to be appointed. Also about dispute resolution between substituted decision makers (nominees) and consumers and or their carers (if the carer is not appointed). This should be faster and more informal than the Tribunal at first instance at least.

- There also needs to be an emphasis on strengths based approaches and building capacity and autonomy and periodic reassessments of capacity to make sure substituted decision making is still being done appropriately and is still required.
- There are also the perpetual issues around recovery orientation and the episodic nature of mental illness. We understand that a person could be a participant in NDIS but not receive support while their condition is well controlled, and then start to receive support again when it recurs. But there is little information about how this will happen practically. How is an assessment triggered if one is a 'dormant' participant in the scheme? Can a carer go to a case manager and advise that the loved on is deteriorating? If you could go for an extended period without requiring support, is it really clear to everyone that you might still have a condition that entitles you to support under the NDIS or is this just a theoretical body of clients who we will never assess as being eligible in fact? (This is important because if you can't have a 'dormant' NDIS 'membership', it is not clear the criteria actually will allow many people with mental illness to participate).

Concern was expressed that aspects of ARAFMI's presentation may not be accurate and/or fully informed. The NDIA offered to meet with ARAMFI to further discuss these matters.

Summary and Next Steps

The actions arising from today's meeting are:

- MHCC to follow-up with NDIA about any outstanding actions from the 20/3 mtg.
- HNEMHS to share the feedback form they have developed for their staff for possible community sector adaption
- HNEMHS to consider whether it is possible to also share a letter they have created for clients to assist in obtaining consent to share information with NDIA and accommodation for the information sharing exceptions under Section 55 of the NDIS act (also for possible community sector adaption)
- Participants would like the next forum to have a focus on sharing people's stories/experiences of NDIS eligibility and access (NDIA, HNEMHS and Partners in Recovery have agreed to this)
- NDIA have extended an invitation to meet with NSW ARAFMI to further discuss family and carer issues
- Anyone wanting to contact the NDIA/Suzi can do so through: engagementNSW@ndis.gov.au.

The next Meeting will be in September (so as to accommodate for the NSW NDIS Organisational and Workforce Readiness Forum being hosted by MHCC, MHCA and NDS on 29/7 in Sydney) The date for this will be advised.

For more information about NDIS MH analysis activity being undertaken by MHCC in partnership with the NSW Mental Health Commission please visit: http://www.mhcc.org.au/policy-advocacy-reform/influence-and-reform/ndis-and-mental-healthpsychosocial-disability.aspx.