The Mental Health Coordinating Council in partnership with the Mental Health Commission of NSW

MINUTES

HUNTER NDIS AND MENTAL HEALTH COMMUNITY OF PRACTICE FORUM
Thursday 20th March 2014 - 10:00 AM to 1.00 PM
Newcastle Jockey Club

Acknowledgements & Introduction
Sage Telford - Senior Advisor, Mental Health Commission of NSW

Welcome and acknowledgement of traditional owners of the land. Acknowledgment of people with lived experience of MH problems.

Update on NSW/Hunter NDIS and Mental Health Activity
Tina Smith - Senior Policy Advisor – Sector Development (NDIS MH Analyst), MHCC.

About 70 people attending this meeting with these mostly being community sector service providers interested in where MH is situated in the NDIA. The number of consumers and carers attending has increased.

Some evaluation results from 23/1 forum are:

- Everyone mostly found the day helpful
- Different people liked different things
- The things people most liked were:
    - Time & opportunity to share with one another
    - Having NDIA/Suzi present and able to immediately respond to any issues arising.
    - More time has been assigned for the above activities including extending the bi-monthly forum to 3 hours.

Recent/forthcoming activity includes:

- 31 January NDIA MH meeting in Canberra to discuss NDIA's development of a MH NDIA Discussion Paper (consultant) – draft is expected soon but circulation uncertain. It will explore: 1) Tier 3 eligibility benchmarking; and, 2) coordination/integration of NDIS and health/mental health services.
- 3 February HNELHD/NDIA meeting focusing on maturation of operational implementation structures including establishment of a MH Working group; membership currently unknown.
- 'Phasing In' of PHAMS and other C'wealth MH program clients in Newcastle LGA from January 2014.
- Growing interest in and concern about people being found eligible/ineligible for Tier 3 funded services.
- Planning for next Organisation Readiness Forum (hosted by MHCC/MHCA/NDS; June TBA – Sydney)
- Presentation to NSW MH Review Tribunal and we may see a growing interest from them in NDIS opportunities at Hunter Tribunal events.

NDIA cumulative implementation quarterly reports have begun to be posted at: www.ndis.gov.au/document/754. Some relevant stats as at the end of December are:

- Of people making an access request, 8.2% have been deemed ineligible nationally (14% for Hunter?).
- Of those who become participants just 2% have psychiatric/psychosocial disability (ie, 57 people nationally).

- This is 0.001% towards the national target of 57K people with psychiatric/psychosocial disability.

How many people with high levels of psychosocial disability might be helped?

Hunter NDIS Implementation

- 2013/14: 3,000 people Newcastle LGA (2,673 'existing' clients and 327 new)
- 2014/15: 5,000 people Lake Macquarie LGA (2,748 'existing' clients plus 2,333 new).
- 2015/16: 2,000 people Maitland LGA (1,200 'existing' clients and 830 new).

'New' clients includes C'wealth funded MH program people assessed as Tier 3 eligible that will 'phase in'. What happened for those assessed as ineligible (ie, is there still a guarantee of service for the three years of the launch?).

Psychosocial Disability (13%?)

- 57/430K in Australia, 19/140K in NSW ,1,300 in launch site 2013/16
- This includes at least 454 new clients but probably higher (ie, the total number of transitioning people with 'primary' psychosocial disability is unknown as is the number of C'wealth 'phasing in').
- Intersect with Partners in Recovery?

Consumer and carer representation/participation in NDIS implementation:

- Journey to identify representatives for today's panel quite challenging (ie, low levels of systemic engagement of MH consumers and carers)
- NSW Consumer Advisory Group (CAG) role in consumer engagement?
- NSW ARAFMI role in carer engagement?
- How to strengthen consumer and carer representation and participation in the Hunter NDIS launch site?

Consumer, Carer and Service Provider Panel – The lived experience of NDIS
The panel participants were:

- Debbie Hamilton - Consumer Representative (independent)
- Joanne Sinclair - ARAFMI Hunter, Carer Representative
- Mark Cliff – RichmondPRA, Service Provider Representative.

Debbie briefly described her experience as a GP who developed Bipolar disorder and the disabling impact it has had on her life. She told us about a recent consumer mtg. held at RichmondPRA to discuss NDIS and eligibility (about 25 people attended). There is a lot of uncertainty for consumers regarding eligibility. One person was assessed as ineligible (the decision is now being reviewed) and other people are reluctant to apply on the basis of this (they were encouraged to apply where eligibility seemed possible). Consumers can have difficulty getting/mobilising/independently to the NDIA due to cognitive impairments. When is a disability 'permanent' and when are 'recovery' based approaches to service delivery encouraged? What is psychosocial/psychiatric disability? We need to also respond to what people assessed as ineligible for NDIS need. The focus needs to be on development of a long term relationship, not just 'goals'.

Jo described how carers and families are often tired and worn out and needing advocacy on their behalf; they are often a frail ageing population. Service providers often perform advocacy functions for carers. What happens when a family doesn't want to be involved in caring? Carers are often in crisis themselves and where do family and carer support services fit in to the NDIS? Where do people with severe disability related to personality disorder fit in to the NDIS? She wondered how services can best work together in the current landscape? Families can feel intimidated by the change processes.

Mark talked about the tensions of community sector collaboration and competition under the NDIS (ie, this is an increasing market economy). RichmondPRA have been transitioning ADHC funded clients

since last July. Where transitioning clients do not have families there is a high impact on existing providers. Once transitioned, care coordination is not being considered in the NDIS support categories and being delivered without reimbursement. The transition process has improved and needs further improvements, especially where a person has no family or friends to support their process. Advocacy is required. NDIA is very open top feedback where there are legitimate service provider concerns but still need to be more flexible. There was more flexibility with ADHC. Continuing inconsistencies in care planning and funding against people's needs. NDIA can't build a relationship with a person over a small number of assessment and planning meetings. The legislation does not speak to duty of care as this relates to transfer of care, especially when moving from one provider to another. People may make choices to change providers that may not be in their interests. It's important to keep speaking with both the NDIA and ADHC about any concerns.

There was encouragement of discussion as to how to strengthen both individual and systemic consumer and carer participation in the Hunter NDIS launch with no practical solutions for achieving this identified and other issues being raised for discussion including:

Someone enquired about what programs are 'in-scope' for NDIS. This is mostly all ADHC funded services and parts of Commonwealth funded MH programs as follows:

- Personal Helpers and Mentors/PHaMS - 100%
- Partners in Recovery/PIR - 70%
- Mental Health Respite Carer Support Program/MHRCSP - 50% (but not Family Mental Health Support Services/FMHSS)
- Day to Day Living in the Community/D2DL - 35%.

NDIA clarified that for PIR this means activity and not funding and that it is an 'in-kind' contribution. The NDIA representative said that they prefer not to use terms like in-scope (for in-kind state/C'wealth program contributions), transitioning (for ADHC funded clients moving to NDIA) or phasing (for C'wealth funded clients moving to NDIA).[1]

Sharing and Reflecting on Experiences of the First Six Months
Key issues that were raised through discussion include:

- Mental health workers and services continue to be in a diverse state of readiness for NDIS with lots of learning occurring through experience.
- Considerable volume of both transitions and new referrals to NDIA continues.
- Tensions between recovery (best presentation) and disability (worst presentation) approaches with NDIS being an insurance scheme.
- Where is consumer and carer participation and advocacy in scheme design and implementation?
- What will happen with Commonwealth 'in-scope' mental health programs?
- Concerns related to 'transition of care' where a person chooses a new provider.
- Need for stronger family based approaches.
- Psychosocial assessment and care planning skills of NDIA staff.
- Trustee/guardian sometimes not aware of NDIA transitions.
- Who provides care/service coordination to support client to implement their plan?
- Direct assist vs other types of support to MH clients (ie, skills required for working with psychosocial disability don't seem to be well understood by NDIA).
- Some people, mostly self-referring, that have been denied access to the scheme have been distressed by this and don't always know the reasons why. They are encouraged to obtain support in getting written reasons why and considering appeals processes.
- Service pricing and portal access continue to be issues but people are becoming more familiar and comfortable with use of the portal.

[1] We note that this is the language being used by the NDIA national office and would welcome alternative guidance on preferred language from the Hunter office?

- Problems with the processes used for assessment of boarding house residents. The client may often present as quite well as a result of the support they receive and/or not have insight into their support received by either the boarding house proprietor or other treatment and/or support provided by community based services (eg, ADHC Active Linking Initiative/ALI). There are also concerns about loss of mobility allowance. This will be useful early experience for when the NDIS extends to Lake Macquarie next year (ie, Riverview boarding house has over 70 residents).
- Not enough experience yet of PHAMS clients phasing in to NDIA but growing concern that large numbers may not be eligible.
- Concerns were raised about there being no ATSI identified positions within the NDIA.
- There were many other questions/comments remaining from participants and they were invited to communicate these to either myself, NDIA and/or HMH as the event progressed and/or after the event.
- One set of issues also related to boarding house resident transitions to the NDIA was received from a participant as follows:
    - The participant describes that a staff member from PRA on King and NEAMI have a shared client (DB) who has a BH-HASI package and is supported by NEAMI staff to attend at PRA on King (previously a free service/social gathering place). My staff member was asked last week, "How are they (PRA on King) going to be paid for DB to attend in the future?".
    - Other questions have come from BH-HASI consumers living at Riverview Hostel post their NDIS/HWNS info session recently. They clearly did not understand the information provided. Clients are asking: How much money will I get? Do I need to choose between my current service providers or can I keep both? Staff are asking: Will BH-HASI consumers lose mobility allowance once their plans are signed off (boarding house residents often use this extra payment for discretionary spending). There are concerns that boarding house residents are going to be significantly disadvantaged as result of losing mobility allowance and will not be able to afford to do anything once their boarding house fees are paid (85% of DSP).

Update from National Disability Insurance Agency (NDIA) Hunter
Suzanne Punshon - Director of Engagement and Funding, NDIA, was represented by Tanya Brunning, Service Delivery Manager.[2]

Tanya responded to some of the concerns above and took others on notice.

As at 26/2, 89 people at NDIA Hunter with 'primary' psychiatric disability and 75 now had plans. The numbers of eligible people with psychosocial disability related to a mental health condition is growing quickly in the Hunter. There was discussion about what might have happened with the other 14?

The MHCA asked what criteria the Hunter trial is using to assess whether someone meets the access requirements for permanent psychosocial disability. Tanya's mentioned factors that Hunter are using to determine whether someone with psychosocial disability meets the access requirement around permanency, such as length of period of illness, and the level of effect it has on someone's life and how this is measured. It would be helpful if we all better understood what criteria is already being used. In the Hunter it sounds like some consistent principles are beginning to be developed and applied well. It would be great to use these as a starting point and look at how we can add value as well as explain the process in a language that is accessible to people with a psychosocial disability and obtain their input.

Discussion of the challenges of engaging mental health consumers and carers in service/systems changes. This is especially the case for consumers with cognitive impairments who have trouble understanding and acting on information and/or who have been traumatised/retraumatised through their life experiences and have trust/engagement and relationship development issues.

Update from Hunter New England Mental Health (HNEMH)

[2] Please note that Tanya is no longer with NDIA and a new primary MH contact is yet to be identified.

Megan Turrell - Rehabilitation Coordinator (Hunter)/Senior Clinical Psychologist - Psychiatric Rehabilitation Service, HNEMH

- 63 referrals to NDIA from HMH inpatient sites
- 19 accepted and some are still being assessed
- Uncertain of how many have been deemed ineligible but some of the reasons why are: insufficient evidence (of disability?); over 65; outside of launch site; not a permanent disability; not substantially reduced functional capacity
- Now auditing HMH community team referrals and also their caseloads to identify potential referrals.

There was discussion about the value of further exploring the characteristics of both the eligible and ineligible groups of people in terms of establishing access/eligibility benchmarks that other might benefit from during NDIS rollout in NSW and nationally.

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

Where are we at?

- Many unanswered questions
- Only one launch site national actively transitioning mental health clients (ie, Hunter)
- MHCA has fundamental policy concerns
- Major implementation challenges

Key challenges relate to:

- Permanency of impairment
- In-scope programs and services
- Early intervention
- Episodic need
- Implications for:
    - Service quality
    - Service access
    - Financial sustainability
    - Links to other systems.

MHCA has been trying to raise awareness of concerns about accommodating psychosocial disability and mental health into the NDIS for some time. While supportive of the scheme, there are many implementation issues to be resolved to avoid creating even more cracks for people to fall through. The MHCA were invited by NDIA to submit a proposal as to how some of these issues might be overcome. In short, the proposal seeks to quarantine the spending on psychosocial disability within the NDIS and ensure some continuity in programs like PHaMS and others that deliver services to people who may not qualify for a full NDIS support package, while some more work is done to get the scheme's design right.

The path forward that has been proposed by the MHCA at the request of NDIA is summarised below:

1. Quarantine funding for mental health/psychosocial disability ($2.1 billion for Tier 3 and Tier 2)
2. Use evidence to better describe the target population for Tier 3
3. Continue funding in-scope services for three years (eg, PHAMS, Day to Day Living, MH Carer Respite).
4. Tier 2 services to be block-funded
5. Re-align assessment and planning processes for Tier 3 participants
6. Extensive consultation and targeted research
7. Establishing formal consultation processes with non-government stakeholders.

The MHCA is seeking feedback on the proposal which is to be discussed at their CONGO (Council of Non-Government Organisations meeting) on 10 April.

The MHCA has worked with the National Mental Health Consumer and Carer Forum (NMHCCF) to develop information for mental health consumers and carers about the NDIS. While the scheme is still in a trial phase and there are a number of issues that are being worked out, the MHCA has developed a series of four fact sheets that are designed to provide consumers and carers with some information about the NDIS and what it might mean for people with psychosocial disability.

These resources are DRAFT only at this stage and the MHCA are keen to receive feedback from consumers and carers about the sorts of things you want included in future fact sheets: contact Travis.Gilbert@mhca.org.au.

Summary and Next Steps

Actions arising from today:

1. MHCC/MHCA to continue to explore ways to enhance individual and systemic participation of consumers, carers and community sector providers in NDIS implementation.
2. 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).
3. MHCC/MHCA advocacy regarding the negative impact of loss of mobility allowance on boarding house residents (and potentially other participants).
4. NDIA and HMH to provide most recent MH 'stats' for eligibility and access at these meetings as an ongoing part of their updates
5. NDIA to remind their admin. That use of the web based 'My Access Checker' is not an access requirement
6. 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
7. NDIA to provide additional information available in regard to plans for deregulation of pricing
8. Sector to provide comments to MHCA on their recent submission to government
9. MHCC to circulate MHCA submission to NDIA with Minutes
10. MHCC to circulate MHCA fact sheets for consumers and carers with Minutes
11. MHCA update to be closer to the front of the Agenda at the next meeting.

Minutes to be sent out with next meeting notice. The next meeting will be held 17 June 2014, 10AM to 1PM, Newcastle Jockey Club.