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

Hunter NDIS and Mental Health Community of Practice Forum
29 March 2016 - 10:00 AM to 1.00 PM
Newcastle Jockey Club

MINUTES

This was the 10th Hunter NDIS and Mental Health Community of Practice (CoP) Forum. The main topic for this event was scheme access. 84 people participated as follows:

- 49 community sector workers from the NDIS trial site
- 17 community sector workers from outside the NDIS trial site
- 5 other people from the NDIS trial site
- 7 other people from outside the NDIS trial site
- 6 consumers.

Note: The order of program activities varied on the day against speaker availability as minuted below.

Acknowledgements & Introduction
Tully Rosen - Senior Advisor, Systems Monitoring & Review, Mental Health Commission of NSW

Tully Rosen provided an ATSI acknowledgement, a consumer acknowledgement and welcomed participants. Tully Rosen spoke about the release of the NSW Mental Health Commission's and NSW Ministry of Health respective 'One Year On' reports (ie, accounting for directions against the NSW Mental Health Strategic Plan 2014-24).

Update on NSW/Hunter NDIS and Mental Health Activity
Tina Smith - Senior Policy Advisor, Sector Development (NDIS Mental Health Analyst) Mental Health Coordinating Council

- Tina Smith gave broad details about the Local Health District level roll out of NDIS in NSW as per bilateral agreement announcement.

- The NDIA 10th Quarter Report indicates that at the end of December 2015, there were 1, 406 NDIS participants with a primary psychosocial disability/PSD and plan nationally and this includes 518 people in NSW.
  However, the 10th Quarter Report did not report upon:

  1. people with secondary PSD/MH condition;
  2. people with primary PSD without a plan;
  3. people with a primary PSD being declined and/or 'choosing' not to access.

- Reported data is not consistent regarding who and what proportion of people have gained access to NDIS packages and the assessment criteria used.

- Many new NDIS reports have been released since the last CoP Forum including:

- ‘Commonwealth Joint Standing Committee on the NDIS Report’ (2nd report)
- NDIS Independent Advisory Council (IAC) Report ‘End of Year Update 2015: Supporting an Ordinary Life for People with Disability’
- ‘NDIS Principles to Determine the Responsibilities of the NDIS and Other Service Systems’ (2nd edition)
- ‘ILC Commissioning Framework’ - Consultation Draft

- Recent NSW NDIS activity includes:
  - Commonwealth & NSW NDIS Operational Plan ‘Commitment’ (December 2015)
  - Flinders NDIS Evaluation
  - Outsourcing of NDIA Local Area Coordination (LAC) functions has occurred. Outsourced until July 2018 to two subcontractors - St Vincent de Paul Society and Uniting – with a third organisation to be identified later.
  - Consultation - NDIS Information, Linkages and Capacity-building/ILC Commissioning Framework: Face-to-face on 6 & 7 April 2016 (Sydney) & 8 April 2016 (Dubbo) and written submissions –by15 April 2016.

- The ILC Commissioning Framework Consultation Draft (December 2015, p. 21) notes that *”… the Agency does not consider there is sufficient clarity to be able to detail the exact role of ILC and the ways in which it will interact with the broader mental health system in this Consultation Draft. The Agency will continue to work closely with the Australian Government as these (national mental health sector) reforms progress”.*

- Other NSW NDIS related activity includes:
  - Release of the 5th MHCC & NSW Mental Health Commission six-monthly NDIS e-newsletter (January 2016; covering period July to December 2015)
  - Future of Commonwealth and State funded MH programs (ie, under mental health reform directions announced 26 November 2015 including new Primary Health Network roles).
  - MHCC seeking clarifications regarding NDIA advice that new NDIS entrant’s tend to have ‘urgent and exceptional needs’ (ie, no definition for this)?
  - MHCC continuing advocacy for consumer and carer systemic participation within ‘co-design’ of the NDIS.
  - Developing new resources to assist with the scaling up of the NDIS in NSW including tentatively named ‘*Guidelines for Everything You Wanted to Know About Navigating the NDIS from a Mental Health Perspective’* and ‘*Guidelines for Establishing a Local NDIS Community of Practice to Enhance Learning and Sector Reform’*.

- National NDIS and mental health related activity includes:
  - NDIA MH Sector Reference Group 5th meeting on 8 March 2016: http://www.ndis.gov.au/document/august-mental-health-sector-communique
  - Projects:
    - NDIA MHA/CMHA Design of Individual Supports Project – completed
    - MHA/CMHA (MHCC) NDIS MH Workforce Scoping Project – completed
    - NDIA Operational Access Review implementation – note that this is the focus of today’s presentation and workshopping.

- The reports of the first two projects have not been made public and MHCC, through Community Mental Health Australia, is advocating for their release.

- Findings and recommendations of the workforce projects are being taken forward by MHCC who convened an NDIS Workforce Development Roundtable in the Hunter on 15 March 2016 and these directions will inform the work of MHCC's Workforce Development Advisory Group.

- Issues arising around Hunter trial site activity include:
    - 'Phasing' in of Commonwealth MH program clients has accelerated (eg, PHaMS & PIR).
    - Appearance of 'time-limited capacity-building plans' – what are these?
    - Access to new 'establishment fee' & 'community participation costs'.
    - Tensions related to new 'coordination of supports' items (ie, organisation doing coordination cannot also provide supports to same individual).
- CoP Forum attendance: At the end of 2015, the forum had 428 participants across 9 events:
    - 178 community sector workers from the Hunter
    - 84 community sector workers from outside the Hunter
    - 110 other people from the Hunter
    - 51 other people from outside the Hunter
    - 5 consumers.

- The future of forum after the trial period continues to be uncertain and early discussions have occurred to identify a sustainable auspice.

Update: Consumer Participation in the NDIS
Michael Macokatic - NDIS, Senior Peer Worker, RichmondPRA

Michael Macokatic began by emphasising that his overall experience of the NDIA trial site regarding participants with mental health conditions/psychosocial disability receiving access to packages had been overwhelmingly positive. Michael Macokatic stated that *"more people are certainly getting access to services that will keep them out of hospital."*

Michael Macokatic stated his views on the access challenges he had experienced as a Senior Peer Worker in the Hunter trial site:

- For drop-in centre consumers in the Day to Day Living (D2DL) program, there were some long-termers (avg. 2 full days/week) finding their support plans are not very easy to understand and so they do not get the hours they wanted because logistics and service type were not taken into account. Some ex-D2DL consumers were now being provided only an hour or two per week, including transport.

- He found that people do not understand the NDIS and can lack confidence to speak up for themselves or to engage with the NDIA. Peer Work is important to supporting people in their access.

- Some clients reported finding phone interviews with the NDIA daunting with in-person discussions being more useful.

- In his experience, plans where a person is not well supported in their access are not always a reflection of their true needs. Some people give up trying!

- There are unclear rules around support providers and support coordination providers. Organisations are having varying experiences around having this rule enforced.

Some participants do not want more than one contact for their services. Concern about the separation of functions for some people.

- There are strong pressures inside his organisation to reduce indirect work as only direct support work is billable.

Q&A:

- NDIA representative (the new NSW Northern Manager, Lisa Short) requested that consumers experiencing challenges for telephone review and/or access experiences let their concerns be known so as to be given consideration for face-to-face processes. She suggested that a list of people not suitable for phone review may be useful.

- Carer noted that her son has the same organisation providing coordination of supports and disability/recovery supports and this seems to be working well.

- There was a discussion about the separation of coordination of supports and provision of disability/recovery supports. Very diverse views on this subject with people requesting further clarity now.

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

Reports have been received by CMOs at the Hunter trial site of 12-month "time limited capacity building plans". NDIA Hunter office have not heard of these.

- Suzanne Punshon opened her report by noting that "Our (ie, the NDIA's NDIS) website is the one source of truth."

- The *Early Childhood, Early Intervention* procurement guidelines have been developed and trialled at the early NDIS launch for young people eight yrs and under in the Nepean Blue Mountains and will be used across all NDIA sites. There is a strong focus on young people in this approach. The procurement guidelines procurement guidelines promote access to natural supports firstly and then consideration of individual plans. They can be accessed here: http://www.ndis.gov.au/news/ndia-announce-first-nationally-consisten

- The LAC for Northern NSW is SVDP. LAC is the face of the NDIS in NSW.There work will start with transitioning in residents from the large ADHC funded residential centres and then supported accommodation and then community-based programs. LAC partners will be in the NDIA system as staff. It is intended to be as integrated as possible. They will be developing first plans for 12 month periods which will practically replicate their existing services. The reason for this was stated to be that the first plan is the best plan while relationships are being developed. This will then be followed by a more self-directed plan the following year. It is expected to be a slower process than the trial site experienced.

- Further comments/discussion of coordination of supports issues. NDIA supports the separation of coordination from disability/recovery support services. NDIA Hunter have been running a monthly forum for registered service providers only since last November to support learning around coordination of supports roles and functions (last Friday of each month at the Newcastle NDIA office). Coordination of supports is all about capacity building. A person with just one provider can be very isolated. The

intent here is to increase choice. Coordination of supports is designed to help people implement their plans.

- Re: NSW Two year NDIS transition period. The NSW bilateral agreement has prioritised ADHC clients during the transition period. **NDIA Hunter does not believe it is likely for there to be spare packages during the two year transition for primary psychosocial disability applicants, unless they are existing Commonwealth funded mental health programs who will be on 12 month plans that reflect current services.**
- The majority of roll out activities in the two year transition period 2016-2018 will be performed by Local Area Coordination (LAC) partners. St Vincent De Paul and UnitingCare have been funded for LAC until 2018. Then the LAC contract will go out for tender.
- Providers are being urged to help their clients get ready by ensuring that records are up-to-date. Help client define their current supports and document it.

Q&A

- Of special note from the day was significant discussion of the implications of the NSW-Commonwealth Bilateral Agreement on mental health consumers. The Hunter branch of NDIA stated clearly that it is very unlikely after June 2016 for anyone with primary psychosocial disability to receive an NDIS package during the two year transition period with this exception of some people transitioning from national mental health programs. CMOs stated concerns for people who may miss out on services and the ramifications on their business planning.
- Concern was expressed about people with psychosocial disability newly accessing the NDIS who currently have very little or even nothing.
- A non-trial LGA person from Port Stephens asked how anyone, and especially you people with mental health conditions were to get help over the next two years.
- Disability Advocacy NSW reiterated the importance of requesting review of access decisions through the NDIA in the first instance before escalating through to the Administrative Appeals Tribunal and noted their available literature about obtaining help with this.
- LAC partners also noted their availability to assist with review of decisions.
- The importance of access advocacy was reiterated.
- MHCC guidance for communities entering the NDIS environment on 1 July 2016 to support people with psychosocial disability in their NDIS access was met with concern by NDIA.

Presentation: NDIS Operational Access for People With Psychosocial Disability Project

Mark Rosser - Assistant Director, Mental Health Practice Approaches, Scheme Transition, National Disability Insurance Agency

- Mark introduced both himself and his new role within the NDIA and explained how the NDIA mental health team is growing.
- In additional to operational access for people with psychosocial disability Mark has been looking also at the early intervention space.
- Reasserted that the NDIS legislation determines access and can't be changed (except through formal review).
- Mark provided comprehensive information about the rollout of the NDIS from a mental health/psychosocial disability perspective and this is documented as Attachment 1.

- Notably:
    - An early intervention gateway is being examined by the NDIA mental health team. It isn't appropriate for most psychosocial disability participants accessing the scheme.
    - The NDIA Operational Access Review for Mental Health recommendations have been assessed and are now being implemented. The details of this will be available in the next NDIA National Mental Health Sector Reference Group Communique.
    - An 'Operational Access Review for Psychosocial Disability Implementation Plan' developed November 2015 has not been made public.

Some key work plan priorities moving forward:

- National Mental Health Sector Reference Group – held quarterly. Communiques published regularly post each meeting
- Establishment of strategy to engage Indigenous people with psychosocial disability and their families and carers
- Enhancement of NDIA materials and processes project specific to psychosocial disability
- NDIA staff resource training kit to enhance skills in understanding psychosocial disability and recovery
- National Community of Practice Network for the mental health sector and NDIA
- Early Intervention literature review
- Comorbidity literature review.

Q&A

- Who supports a person with psychosocial disability in their access to the NDIS?
- The Access Request Form, which is the gateway to the NDIS, does not lend itself to capturing the information required for people with psychosocial disability.
- Some potential participants seem to lack insight into their needs and are difficult to engage (ie, need more support than other to access the NDIS). Is this 'choice'? Should this be an indicator that guardianship arrangements a required for a person?

Small and Large Group Reflections on NDIS Access for People with Psychosocial Disability

Tina Smith & Tully Rosen

It is notable that participants were more willing, and/or the process better allowed them, to provide written rather than verbal feedback. All feedback is provided as Attachment 2. Key themes arising from the feedback are summarised below.

Participants were asked to consider as individuals, small groups and as a large group the following questions:

Have you or someone you know decided not to take part in/apply for the NDIS?
(If yes, what were some of the reasons for this? What was this experience like for the person?)

> Key themes: The need for NDIS access advocacy/support for people with psychosocial disability. Relationship development supporting outreach and engagement for NDIS access matters. Language for NDIS access matters.

Have you or someone you know applied but been told that you are not eligible for the NDIS?
(If yes, what were some of the reasons for this? What was this experience like for the person?)

> Key themes: Sufficiency of evidence for NDIS access against the legislative requirements and operational guidelines. Challenges accessing funded services (for both participant and due to 'market' failure).

What, if any, appear to be access barriers to the NDIS for people with psychosocial disability?
(Are there specific barriers that you have noticed over the course of the trial that you think others need to be more aware of?)

> Key themes: 'People not being motivated to participate' (ie, people having a range of mostly cognitive-behavioural functional deficits that make it difficult for them to engage for either NDIS access and/or plan implementation).

Any other burning access issues not discussed so far today?:

- Feedback has been reported of an increase in guardianship applications in the trial site. The NDIA (Hunter) noted that they have not observed an increase in guardianship applications as a result of the NDIS.
- Several people shared stories of difficulties accessing the NDIS for people with disability related to a chronic health condition (ie, where the person also had a mental illness and needed disability/recovery support to access mainstream health services). This may be related to healthcare support previously provided by NSW Home and Community Care (HACC) services not yet being fully resolved.
- Eligibility issues seem to be mostly related to not having adequate evidence of disability.
- The continuing reconciliation of disability and recovery language and concepts also continues to sometimes be an access barrier.

Update from Hunter New England Mental Health (HNEMH)
Kylie Gifford, NDIS Access Coordinator, Morisset Hospital, HNE LHD

Rather than a service wide update, Kylie spoke about the NDIS experiences of people at Morisset Hospital as CoP Forum participants have been asking to learn more about this: 'From Patient to Participant: Making the NDIS work for people at Morisset Hospital' (see Attachment 3). Several positive stories were provided of consumers obtaining NDIS packages allowing safe and high quality transition plans from hospital to proceed; in one case, for a man who had been residing at Morisset Hospital for 20 years.

Summary and Next Steps

The learning and key themes arising from the consultation informs MHCC's ongoing NDIS advocacy as this relates to the unmet needs of people with mental health conditions. This will include written correspondence to National and State governments regarding experiences across the NDIS trial and requesting additional access data.

Forthcoming events include:

- ILC Commissioning Framework Consultation 6 & 7/4 Sydney & Dubbo 8/4 and written feedback by 15/4
- Next and possibly last Hunter NDIS and MH CoP Forum is 21 June 2016 and Janet Meagher, a consumer representative to the NDIS Independent Advisory Council (IAC) and IAC representative to the NDIS Mental Health Sector Reference Group will be joining us for a celebration of the achievements of the three year NDIS trial in the Hunter!

<u>Actions Arising</u>

- Obtain and distribute NDIS guidelines related to coordination of supports items with Minutes.
- Follow-up on concerns about NDIA (Hunter) advice that there will be few opportunities for new entrants to the NDIS over the next two years other than those with 'urgent and exceptional needs' (ie, this contradicts government advice that NSW scope for new entrants is 31,217 from 1 July 2016 to 30 June 2018 and rising to 57,621 by 30 June 2019, inclusive of some Commonwealth funded mental health program clients).
- Seek greater understanding and advocate regarding the position that Commonwealth funded mental health program clients and other ADHC funded clients with primary psychosocial disability in scope for NDIS will for the first 12 (or more?) months continue at their current and (mostly low level) of funded services.

Attachment 1

NDIS Presentation
NDIS Operational Access Review for Psychosocial Disability Update

Background to the NDIS

- 2008: Commonwealth 2020 Summit proposes a national disability scheme
- 2010: Productivity Commission conducts enquiry in to long term disability care
- July 2011: Productivity Commission submits report to government
- Oct 2011: COAG agrees to need for reform – taskforce develops scheme design
- Dec 2012: COAG sign agreement to trial the Scheme
- Mar 2013: NDIS Act 2013 establishing the NDIS and NDIA passed
- Apr 2013: Bilateral agreements with trial sites signed
- 1 July 2013: Trial sites in VIC, NSW, SA and TAS start
- 1 July 2014: Trial sites in ACT, NT and WA start
- 1 July 2015: Early transition in Nepean Blue Mountains NSW begins
- Sept 2015: VIC and NSW bilateral agreements signed
- Dec 2015: SA and Tas bilateral agreements signed
- April 2016: Early transition in QLD begins
- July 2016: Roll out begins in VIC, NSW, SA, ACT and Tas

Consultative and team approach:

- Listen, Learn, Build, Deliver
- Multiple branches working within NDIA that touch on understanding access for people with a psychosocial disability
    - Mental Health Team within Scheme Transition
        - Strategic Advisor
        - Director
        - Assistant Director
        - Project Officer and
        - Programs Analyst
            - NDIA - Mental Health team is guided by the collaborative input from the National Mental Health Sector Reference Group which includes people with the lived experience of psychosocial disability and sector representatives
            - NDIA has an internal Mental Health Community of Practice which focuses on work it can do as an agency to ensure our practices are appropriate and effective for people with psychosocial disability
    - National Access Team
    - Scheme Actuary – data
    - Markets and Providers

Psychosocial disability data:

Productivity Commission estimated 56,880 people with a primary psychosocial disability would be eligible for individual support packages. This equates to approximately 13.8% of the total estimated tier 3 population

- As of 31 December 2015, there were 1,681 participants with a primary psychosocial disability and 751 NDIS participants with a secondary condition of a psychosocial nature.

- Data from the NDIS Barwon trial site continues to be the most complete, and access rates for people with a primary psychosocial disability generally align with the Productivity Commission estimates.
- The Barwon trial site proportion of participants with a psychosocial disability is 14.2% which compares favourably to the Productivity Commission estimates of 13.8%.
- A further 55,000 people with a primary psychosocial disability are projected to be included at full Scheme.
- 72% of participants submitting an access request with a psychosocial disability have been found eligible
- 1404 of the 1681 primary psychosocial participants or 84% have an approved plan
- 151 of the 1404 (participants with an approved plan) have accessed the scheme through the early intervention criteria
- The proportion of participants with a primary psychosocial disability in NSW has risen from 9.2% (30 September, 2015) to 9.6% (December 2015)
- $69.4 million has been committed to supports for participants with a primary psychosocial disability in Victoria and NSW.
- Scheme Actuary tracks all data for participants in the Scheme: this drives continual improvement. Quarterly reports are produced.

Accessing the NDIS:

- People with disability who meet the access requirements will become participants
    - Access requirements refers to 'disability' and or 'early intervention' requirements.
    - Sections 24 and 25 of the NDIS Act 2013.
- People with disability enter the NDIS through multiple channels
- There will be a gradual intake of participants around Australia
- People in areas where the NDIS is active can contact the NDIA to ask questions and request an Access Request Form

Disability requirements:

Accessing assistance from the scheme requires that a person must:

- Have permanent disability ("person has a disability that is attributable to one or more impairments attributable to a psychiatric condition….are, or are likely to be permanent")
- The disability must have a significant impact on day to day life and on the person's ability to participate in the community ("severity of impact on functioning may fluctuate and may improve, determined when the impairment is fully treated and stabilised – residual and LT)")
- The person will ("likely") need supports for the rest of their life

Early intervention requirements:

Accessing assistance from the scheme requires that a person must:

- Has one or more impairments attributable to a psychiatric condition….are, or are likely to be permanent")
- The CEO is satisfied that provision of early intervention supports for the person is:
    - Likely to reduce future needs for support
    - Likely to benefit the person by;
        - Mitigating or alleviating functional impacts
        - Preventing the deterioration of functional capacity
        - Improving functional capacity
        - Strengthening the sustainability of informal supports
    - A person does not meet the early intervention requirements if the CEO is satisfied that early intervention support for the

person is more appropriately funded or provided through another service system

NDIS and mainstream systems:

- The NDIS is not intended to replace the supports or services provided by other mainstream systems
- Wherever possible we assist participants to access mainstream systems
- Key principles determine whether the NDIS or another system is more appropriate to fund particular supports
- A participant's plan may include a range of supports provided by informal, mainstream and community networks. Some of these may be funded by the NDIS.

Interface with mainstream health/mental health services:

- The health or mental health system will be responsible for:
  - Treatment* of mental illness, including acute inpatient, ambulatory, rehabilitation/recovery and early intervention, including clinical support for child and adolescent developmental needs;
  - residential care where the primary purpose is for time limited follow-up linked to treatment or diversion from acute hospital treatment; and
  - the operation of mental health facilities.
- *Treatment is defined as activities associated with stabilisation and management of mental illness (including crisis, symptom and medication management) and establishment of pathways for longer term recovery.

Interface with mainstream health services:

- The NDIS will be responsible for ongoing psychosocial recovery supports that focus on a person's functional ability, including those that enable people with mental illness or a psychiatric condition to undertake activities of daily living and participate in the community and in social and economic life. This may also include provision of family and carer supports to support them in their carer role, and family therapy, as they may facilitate the person's ability to participate in the community and in social and economic life.

Operational Access Review for Psychosocial Disability:

- The project commenced in November 2014
  - **Workshop 1** of the project took place on 28 January 2015, a key outcome of this was the establishment of 5 Working Groups:
    - **Eligibility,**
    - **Early Intervention,**
    - **Language, Processes, Products and Narrative,**
    - **Engagement an Outreach, and**
    - **Population Data**
- The theme based Working Groups met between February and May 2015.
- The outcomes of these Working Groups were recorded and were considered at **Workshop 2** of the project which took place on the **15 May 2015**.
- Feedback from Workshop 2 helped to refine and agree the contents of recommendations. The recommendations were then submitted to:
  - **NDIA Mental Health Sector Reference Group on 11 June 2015**
  - **NDIA Executive Management Group (EMG) on 28 July 2015**
    - **Including the framing of recommendations into two clusters**
      - '*Operational and Practical* ' Recommendations (1.1-1.16) and
      - '*Laying the Foundations'* Recommendations (2.1 – 2.23)
  - **NDIA Mental Health Sector Reference Group on 17 August**

- The EMG recommended that working group recommendations be framed into an Operational Access Review for Psychosocial Disability Implementation Plan – developed November 2015

Some key issues around psychosocial disability:

- Language:
  - Notions of permanent and likely to be permanent
  - Variations in intensity
  - Recovery
  - Definition of psychosocial disability
- Eligibility and access:
  - Establishing evidence of disability; who, how, what is evidence, what forms
  - Outreach and hard to engage groups; how to engage, who will do this
  - Early intervention
- Overall understanding of recovery and the NDIS, who the scheme is for and how to access it – sector wide engagement, information gathering and exchange, training for NDIA staff and wider sector

Some key projects and development around psychosocial disability:

- Review of early intervention gateway for people with a primary psychosocial disability
- National Communication and Engagement Events planned for mid 2016
- Liaison with DoH and DSS about PIR and PHaMs providers supporting access readiness and pre planning readiness
- Reference package for psychosocial disability
- Release of the Individual Supports Design project (NDIA/MHA)
- ILC and LAC roles: Providers have been announced in NSW: Uniting and St Vincent de Paul. Recruitment and training is underway.

Some key work plan priorities moving forward:

- National Mental Health Sector Reference Group – held quarterly. Communiques published regularly post each meeting
- Establishment of strategy to engage Indigenous people with psychosocial disability and their families and carers
- Enhancement of NDIA materials and processes project specific to psychosocial disability
- NDIA staff resource training kit to enhance skills in understanding psychosocial disability and recovery
- National Community of Practice Network for the mental health sector and NDIA
- Early Intervention literature review
- Comorbidity literature review

Questions:

Visit: www.ndis.gov.au
Phone: 1800 800 110
8am-8pm eastern standard time weekdays
Email: enquiries@ndis.gov.au

Attachment 2

FEEDBACK FROM SMALL AND LARGE GROUP WORK: REFLECTIONS ON NDIS ACCESS FOR PEOPLE WITH PSYCHOSOCIAL DISABILITY

Summary

Participants were asked to consider as individuals, small groups and as a large group the following questions:

- Have you or someone you know decided not to take part in/apply for the NDIS?
- Have you or someone you know applied but been told that you are not eligible for the NDIS?
- What, if any, appear to be access barriers to the NDIS for people with psychosocial disability?

It is notable that participants were more willing, and/or the process better allowed them, to provide written rather than verbal feedback.

Large Group Feedback following Small Group Work (ie, verbal)

<u>Have you or someone you know decided not to take part in/apply for the NDIS?</u>

- Those without a strong advocate or carer to help engage
- Rare for community managed organisations to hear this from clients
- Some families who can afford private care choose to go it alone

<u>Have you or someone you know applied but been told that you are not eligible for the NDIS?</u>

- Nil responses

<u>What, if any, appear to be access barriers to the NDIS for people with psychosocial disability?</u>

- Consumers not ready to make use of plan
- Low level of self-awareness (of problems)
- People who struggle to maintain support worker relationships
- Discussion of Public Guardianship access issues
- Cultural competency
- Discussion of complexities of siloing of physical health care supports and disability supports in NDIS planning/plans
- Unresolved issues related to Home and Community Care Program transition

Written Feedback

Have you or someone you know decided not to take part in/apply for the NDIS?

- Stigma of deficit based language
- Trust of a governmental body with personal information (or lack thereof)
- Carer dependence & co-dependence?
- Difficulty with engagement
- Awareness insight?
- Lack of information "will I lose my DSP."
- Difficulty for access
- Yes, because of lack of insight into own condition
- Yes, they did not want the complications – I have tried to discuss futures planning, but for now parents have been happier controlling the supports for their children
- Does not want to rely on government money
- Trust
- Wording "Disability"
- Stigma
- Language
- Fear
- Homelessness
- Not wanting money/funds from the government
- Suspicious of an "Insurance Scheme" and what that means
- Stigma attached to accessing the scheme
- HNEMH – number of clients being offered support to access NDIA –declining due to characteristics of illness such as poor insight, poor engagement
- Evidence of disability maybe used in custody dispute
- Cultural issues, aboriginal participants eg Data – meet with agency - participants
- Finding the process very hard without support
- People not utilising plan as people are not sure what next
- Contact with planner
- Taking months to find service provider
- Person not accepting of mental health diagnosis – limited insight into why life may have periods of chaos/homelessness/hospitalisation

Have you or someone you know applied but been told that you are not eligible for the NDIS?

- Evidence not sufficient
- Not supported during application process
- Where engagement has not been fully achieved
- Difficulty when trying to support person – making appointments to do pre-planning?
- Yes, person with chronic schizophrenia & low level auditory hallucinating very early in trial. 3 months to make a decision and no written reason. Able to get some home cleaning services via Community Options but no other socializing activities etc
  Now Community Options not existing and Home Care services using same criteria as NDIS. Concerned for access to services for people falling into this situation. Can Ability Links really deliver on all these needs? – No[1]
- Asking for extra information/diagnosis/reports
- PWS would not be bothered chasing or engaging current diagnosis
- Initial application but then when declined just walked away
- Yes, mainly due to not enough evidence as functional Capacity Assessments costs and is out of reach of most individuals
- Not suitable/appropriate evidence
- Pre-approval support
- Health
- Yes, people with a mental illness are often unable to identify the impact of the mental illness upon function, when well, however, when unwell, the MI has a major impact upon ability to function
- Yes – most cases insufficient evidence to make an eligibility decision
- Time and level of investment required to challenge & override ineligible decisions.
- ARF imply minimal information required resulting in additional info requests and extended decision making time-frames sometimes up to 2 months.
- Out of area
- Lady with an intellectual disability had a stroke was receiving (no?) services then funded
- Gaps between NDIA eligible and Centrelink – needs
- Different line items that one funded i.e. families
- No early intervention approach i.e. siblings/families
- Can not get funding for literacy intervention case by disability
- Not having an address in the trial site e.g. in prison, no address on release
- Person “has adequate supports in place” is seeing a psychologist for PTSD
- When mental health and physical health are part of a season life. The impact and continuance of anxiety, depression and symptoms are not recognised? Either one or the other but both identified in depth when applying
- Female, chronic major depression, morbid obesity & severe lymphedema. Accepted as psychosocial disability. Depression severely impacted by physical limitations (unable to walk or even transfer off the lounge due to lymphedema) and her health issues are essentially untreatable, however, because it’s considered a health issue NDIS cannot fund the equipment she needs to transfer, however, while she remains an invalid her mental health will not improve and no other funding is available.
- Yes, but out of area
- Experience of lack of understanding (Medicare - counselling not paid for)
- The more debilitated by illness, the harder it is to seek support

[1] See further comment highlighted below.

What, if any, appear to be access barriers to the NDIS for people with psychosocial disability?

- Reluctance by individuals to engage
- Discouragement by significant others (e.g. BH proprietors)
- Ineligibility/disengagement with MH system
- Language deficit?
- Larger and difficult for access – Processes – finding evidence, completing forms
- Stigma – shame about getting a package
- Refer to person (case) above. As a support worker I tried to engage MH community health worker who discouraged application by saying that client's demotivation and lack of initiation (attributed to his chronic schizophrenia) would make uptake of any planned services improbable.
- Lack of advocacy/explanation/discussion at initial stage around developing a plan. The plan roll out.
- Need to identify primary support/advocate to help individual
- No or minimal contact with health/services
- Waiting on paperwork to arrive by spot – would be easier to download from the internet
- Insight about illness & functional needs
- Evidence, to support diagnosis
- Difficulty for some clients to articulate needs and self-advocacy skills
- Access to the Scheme for eligibility while in prison when no address in the trial site.
- GP's not understanding the Scheme to assist with filling out ARF
- Admin vs Planner
- Inconsistency in Plans
- People that haven't accessed all support because of barriers? – need fight to get refunded
- The illness itself is a major barrier
- Contact with planner
- Not knowing how/where to go
- Gaps when services are transitioning to NDIA
- Funding not matching the capacity versus ? need to a ?????
- Degree of disability
- Access to health records
- Financial prohibitors, inconsistency with changing planners
- Many people with psychosocial disability often have no supports, ??? or consistent medical support unless they have connections to mental health Acute Care. Many people with psychosocial disability have co morbid conditions and self-medicate to manage their conditions. Trust issues re mental health system.
- The understanding of funding by people
- The Planners/Plan no discussion. Plan is in place and did not capture person's immediate choice (big lean toward capacity building – NOW). Service providers and person can work together towards Capacity Building again. It should not be either/or
- Female, severe anxiety, depression, PTSD (complex trauma). Meniere's disease (vertigo) Fibromyalgia and chronic fatigue. Has been refused access for psychosocial disability. I am not sure why (after a long discussion with the assessor as her treating psychologist), however, it appears that her mental illness was not considered chronic enough, even though I clearly stated she had experienced anxiety since childhood and described functional difficulties.
- People are reluctant/afraid of Scheme

Attachment 3

HNEMH Presentation
'From Patient to Participant: Making the NDIS work for people at Morisset Hospital'

Morisset Hospital:
- Inpatient
- 91 Beds
- Non-Acute
- Rehabilitation and Recovery Focus

Complex client profile:
- Severe Mental Illness-many positive and negative symptoms
- Socially isolated / poor engagement skills
- Limited or no insight into their MI and functional deficits
- Dually diagnosed e.g. drug and alcohol, cognitive impairment
- Comorbidities - physical health issues
- Forensic issues - risk issues, MHRT
- Limited informal support networks
- Complex family dynamics
- Poor literacy and numeracy skills
- Difficulty in sustaining tenancy and employment.
- Childhood Trauma
- Family Violence

Morisset landscape pre-NDIS:
- Average stay for clients would vary between 1-3 years
- Traditionally supported on discharge with HASI packages (Housing and Support Initiative) Block Funding
- On average – 8 to 10 discharges per year –variety of HASI packages (Low to Very High)
- 24 Hour HASI packages only available in Tamworth
- Prolonged hospital admissions due to resources not meeting the level of support required.
- Shortfalls in safe and affordable housing, and suitable supported housing models
- Limited mental health community services/ programs to engage long stay clients

Mental health landscape changes:
- Potential of NDIS funding realised very early by Social Workers at Morisset Hospital and ISHMU (psychiatric rehabilitation facilities).
- Prepared and submitted a number of applications for clients at ISMHU (Newcastle LGA) on 1st July 2013 for trial purposes – **first three people accepted nationally**.
- New participants in the three LGAS could apply for the scheme providing opportunity for clients at Morisset Hospital.
- Majority of people at Morisset Hospital met the NDIS eligibility criteria.
- Clients assessed for suitability and readiness for community living and NDIS activity commenced.

NDIS experience for PRS at Morisset Hospital: Eligibility:
- For our population, if a client is <65 years old, they will most likely be NDIS eligible
- Clients required high levels of clinical support to understand and access NDIS.
- Most issues around eligibility for our service have been about:
  - Supplying adequate information re: eligibility criteria
  - Using appropriate language (which for the purposes of eligibility is disability focused).

  - Most clients at Morisset hospital made eligible by NDIS.
- Clients will require individualised transitions to community living.

Some challenges so far:

- Additional workload for clinical staff in supporting NDIS applications and planning processes.
- Duality in language:
  - For NDIS eligibility language is disability focused (of permanency, enduring, lifelong, deficits). This extends to having very high needs items approved for NDIS plans (e.g. if a client needs two support staff)
  - For NDIS plans (and disability and mental health services) language is recovery focused.
    - **Consumer choice** and ability to negotiate NDIS processes is extremely difficult without high levels of support for our most complex and vulnerable clients.
- Access to suitable housing and housing models. Lengthy wait list for social housing properties.

What has been helpful so far:

- Extra resources (staff positions)
- Good communication pathways
- Developing strong links with the local NDIS offices
- Developing strong links with the CMO sector
- Clear Governance & meeting structure.

NDIS participant's stories

<u>Story 1</u>

- Mr SA – 45 yo man, patient at Morisset since 2008. From a regional area of NSW, no family locally. In cottage program, semi-independent, will require a medium level of support with activities of living when in the community.
- BARRIERS TO RECOVERY: Unable to access supervised overnight leave, only able to see his family twice a year due to distance and associated expenses.
- NDIS plan includes: funding to access to the supervised overnight leave program through SF, and funding to pay SF staff to accompany(escort) Mr SA to and from his home town, to spend a period of supervised leave with his family.
- CLINICAL BENEFITS: This will progress his rehabilitation through increased overnight leave in the community, and contact with community support services and his family in his home town (during leave with family).

<u>Story 2</u>

- Mr DG, 55 yo man, from a CALD background, needs medium to high levels of support and supervision, currently residing in the MSU (since 1996). Already supported by SF for local supervised day leave (MHDAO Funded Program).
- BARRIERS TO RECOVERY: Family and cultural contact extremely important, but only able to be facilitated every few months, as family in Sydney, and travel is difficult.
- NDIS plan includes: funding for two SF staff to accompany/escort Mr DG to Sydney once a month to see his family, and be involved in cultural activities. Funding also provided for Mr DG to access literacy and numeracy program, and learn to play the guitar.
- CLINICAL BENEFITS: Increased visits to family reduce Mr DG's anxiety, improves his quality of life, meets some of his cultural needs, and maintains the family connection. May lead to supervised overnight leave in the future.

Story 3

- Ms GC, 55 yo woman, resident at Morisset Hospital since 2008. Currently transitioning into her own home in the community with the support of a HASI package, which provides daily contact between the hours of 8am and 8pm.
- Ms GC is finding it increasingly difficult to remain in her home overnight, and has requested overnight support. Transition plan stopped until this can be sorted out. *This was noted by mental health service as a major barrier to successful transition.*
    - NDIS plan includes funding for support workers overnight. Transition is able to re-commence, with two providers now working with GC to provide support requested.

Story 4

- A group of clients is identified as needing a supported housing model in the community.
- Based on - consumer choice to live with other people and functional assessment - medium to high support
    - ongoing mental health symptoms,
    - cognitive challenges,
    - personal vulnerability and safety, social isolation,
    - length of stay in hospital (step down process),
    - physical health needs.
- Offering 16/24 hour (overnight) support, with NDIS funding.
- CMO's head lease private rental accommodation in a variety of locations.
- clients transition between hospital and community over period of time.
- Five clients discharged and living successfully in the community, four currently transitioning.

Opportunities for clients at Morisset:

- 50 + clients have been supported and are now NDIS participants.
- All potential NDIS clients will be supported in accessing the scheme by the end of April 2016.
- 15 clients have been discharged from Morisset Hospital.
- Positive relationships have been developed with NDIS service providers, traditional and new services.
- NDIA onsite engagement arrangement was extended to Morisset hospital.
- Clients continue to transition at different levels