Mental Health Commission of New South Wales

The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

Submission by Mental Health Commission of New South Wales to the Joint Standing Committee on the NDIS

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Mental Health Commission of New South Wales
Locked Bag 5013
Gladesville NSW 1675
T 02 9859 5200
F 02 9859 5251
E mhc@mhc.nsw.gov.au
W www.nswmentalhealthcommission.com.au

The Mental Health Commission of NSW

The Mental Health Commission of NSW is an independent statutory agency responsible for monitoring, reviewing and improving mental health services and the mental health and wellbeing of the people in NSW. It works with government agencies and the community to secure better mental health and wellbeing for everyone, to prevent mental illness, and to ensure the availability of appropriate supports in or close to home when people are unwell or at risk of becoming unwell.

The Commission promotes policies and practices that recognise the autonomy of people who experience mental illness and support their recovery, emphasising their personal and social needs and preferences as well as broader health concerns.

The Commission is guided in all of its work by the lived experience of people with a mental illness.

The Commission works in three main ways:

- Advocating, educating and advising about positive change to mental health policy, practice and systems in order to support better responses to people who experience mental illness, and their families and carers.
- Partnering with community-managed organisations, academic institutions, professional groups or government agencies to support the development of better approaches to the provision of mental health services and improved community wellbeing, and promote their wide adoption.
- Monitoring and reviewing the current system of mental health supports and progress towards achieving the Actions in the Strategic Plan, and providing this information to the community and the mental health sector in ways that encourage positive change.

Should you wish to discuss any of the issues raised in this submission in more detail please contact Ms Sarah Hanson, Executive Officer,

The Transition of Commonwealth funded services to the NDIS

The Commission is concerned that the full transition of Commonwealth funded services to the NDIS will see a cohort of individuals left without appropriate services. While the Commission welcomes the Commonwealth Government's decision to extend the funding of these services until July 2019 to allow for the full roll-out of the NDIS, this should be seen as an opportunity to consider the issues arising and develop appropriate local arrangements to ensure the needs of individuals continue to be met.

Both PHaMs and Partners in Recovery (PiR) though rolled out nationally, have been developed locally. This approach has not only ensured equitable access to services, but importantly that those services are responsive to local need. The NDIS should have regard to the understanding of local needs developed by these services during the roll-out, particularly as it relates to the Linkages and Capacity Building Framework.

For example, one of the key benefits of PHaMs is that it does not require a person to have a formal diagnosis to access the service. This was a critical factor in terms of ease of access and providing a 'soft' entry point for those who otherwise may not approach traditional mental health services. It also allowed PHaMs to operate on a 'no wrong door' approach by welcoming people in, and supporting them to access appropriate services through a warm referral process.

Individuals often approach PHaMs at a point of crisis, where immediate support is required before considering issues such as formal diagnosis. For many, this short-term crisis based support is sufficient to enable their lives to be stabilised without the crisis escalating to the point where they have an ongoing functional need that would make them eligible for an individualised package. Such a mechanism is equally vital to the success of the NDIS and should be considered for commissioning through the Linkages and Capacity Building Framework.

While PiR is focussed on providing support to individuals with severe and persistent mental illness and complex needs, the role of the PiR was much broader than individual care-co-ordination that may now be incorporated into an individual package under the NDIS. Importantly, PiR was also about building community capacity by drawing together organisations and agencies to work innovatively together to both close gaps in traditional service delivery and referral pathways, as well as to wrap around particular individuals. This is clearly relevant to the Linkages and Capacity Building Framework, but this activity cannot be seen as entirely separate from the individual care co-ordination role. It was by understanding individual experience that innovative solutions were able to be developed and there will continue to be a need of understanding and developing solutions for systemic issues arising from individual experiences under the NDIS. This will require some form of co-ordinated communication between those involved in individual planning or care-co-ordination and those involved in Linkages and Capacity Building projects under the NDIS.

The Commission acknowledges that solutions to systemic issues will not only relate to services funded through the NDIS but also other key sectors, particularly services commissioned or provided by Primary Health Networks (PHNs) and Local Health Districts (LHDs).

The NDIS is being rolled out at the same time as key mental health reforms at both the national and state level. There is great alignment of the intent behind these reforms, for a more responsive, personalised, and recovery focused system of care and support for people who experience mental illness.

However, the transition period is also a time where risks emerge if the planning for the implementation of the various reform efforts are not carefully co-ordinated and approached in a flexible manner to ensure no avoidable harms arise. The NDIA needs to be alert to the danger that others may prematurely withdraw services assuming they will be covered under NDIS, particularly where there is a transfer of a program and there is uncertainty as to whether previous service users will be eligible for the NDIS.

There is therefore an urgent need for the NDIA to work co-operatively with PHNs and LHDs during the transition process to ensure service planning and development is responsive to local needs and is holistic in its considerations, without one agency assuming what will be provided by others. However, equally as critical will be for these agencies to utilise their flexible funding as appropriate to ensure that there are no unintended consequences for individuals who live with mental illness during this important reform period.

Planning Processes

Feedback the Commission has received regarding consumer and carer experience during the Hunter trial site suggests that the NDIA was responsive to adjusting the planning process to respond effectively to the different needs of individuals with a disability that impacts on their capacity.

However, it is unclear the extent to which these lessons have been able to be applied to the broader roll-out, particularly noting that in NSW the initial emphasis is on transitioning current clients of Ageing, Disability, and Home Care, which includes few individuals with a psychosocial disability related to a mental illness. There is a real risk that the hiatus in the full-scale integration of individuals with psychosocial disability into the NDIS during the transition process will lead to a loss of skills and knowledge gained during the Hunter trial, and that systems put in place will not appropriately accommodate the needs of individuals with a psychosocial disability.

The Commission therefore supports the call for planners to develop expertise in particular disabilities to ensure that they are able to provide appropriate support through the planning process and develop a proper understanding of the range of needs particular cohorts are likely to require.

The Commission also supports the call for further work to be undertaken in supporting individuals with a psychosocial disability related to a mental illness to be able to communicate their goals and aspirations. This may be through a range of mechanisms from coaching or mentoring individuals around their rights, through to the introduction of individual advocates or supporters for individuals with more pronounced impairments related to their capacity, particularly for those individuals who do not have a carer or friend who is able to support them through the application and planning process.

Individuals working in this system will need to have a strong understanding of capacity and how this might vary depending on the person's condition at the time, and the nature of the decision. As well as working as appropriate with any nominated Guardian, the planning system will need to look at the continuum of supports that may be required to enable an individual with a psychosocial disability to make decisions regarding the nature of supports they require.

Another relevant aspect of the planning process for individuals with a psychosocial disability related to a mental illness is that it will be common for this cohort to also be receiving services from other sectors, particularly the health sector. A key aspect of the planning will therefore be the extent to which the different supports the individual requires are co-ordinated and work co-operatively. This may require care co-ordination to be part of the planning process itself, rather than simply part of the package an individual may receive.

The Commission notes that significant effort has been put into developing a process where cross service/sector planning can occur for a person with complex needs during the transition process. Such a model will be required to continue once the NDIS is fully established and the Commission would further suggest that the principle of joint planning be applied to all people who have multiple service providers.

Finally, the Commission notes concerns that have emerged from carers in relation to the NDIA's processes, particularly around planning. The *Carer Recognition Act 2010* makes it clear that 'Carers should be considered as partners with other care providers in the provision of care, acknowledging

the unique knowledge and experience of carers'[1]. This needs to be fully recognised during the planning process as carers will inevitably be a key component in the implementation of any individual package.

Outreach services and Linkages and Capacity Building Framework

Outreach should be seen as a core aspect of the work of the NDIA. Often people with a psychosocial disability are known to a wide range of community services. The NDIA needs to tap into the existing network of government and non-government providers, including services that are not delivering specific mental health and disability support but are providing services and programs to the community such as libraries, community centres, neighbourhood centres, local councils, housing and homeless services, and charities.

The NDIA therefore needs to invest in local network forums, whether as part of outreach or through the Linkages and Capacity Building Framework, to work with these agencies to identify individuals who may be eligible for the NDIS, but for whatever reason have not been part of the cohort transitioning from state based disability services or otherwise referred.

This process should recognise that a large proportion of individuals in this cohort will have a history of trauma which will impact on their willingness to reach out to seek assistance, their faith in traditional services, and the time it takes to build a trusting relationship with those involved in the process (from planners through to service providers). Outreach activity may therefore need to be assertive and repeated to enable trust to be built, and the processes that follow will need to build on this trust rather than re-traumatising (e.g. not having multiple people ask similar questions).

A recent example of the benefit of assertive outreach was made known to the Commission in relation to a young adult with an intellectual disability and a mental illness who has always had difficulty engaging with service providers. He was known to his local PiR, and although he had chosen not to engage with the service, the PiR Support Facilitator continued to engage with him and his carer. Through the building of this relationship, when the NDIA was rolled out to his area, the PiR Support Facilitator was able to flag that he was a person at risk who was in need of specialised disability support services and he was then placed on a priority list. The process that occurred shows how proactive identification can assist the NDIA identify people in dire situations. It also took pressure off the man's carer who was exhausted from trying to identify appropriate supports and was grateful to someone reaching out to them.

Another important element for the Linkages and Capacity Building Framework will be the identification of key community based programs which may not be applicable for individual packages, but are critical community supports. For example programs such as Club Houses run by One Door Mental Health (formerly Schizophrenua Fellowship) and Men's Sheds provide a sense of community for many individuals with a disability, as well as providing them an opportunity to engage in meaningful activity. Support for such initiatives should be considered as part of the Linkages and Capacity Building Framework as they provide important social connections that are critical protective factors for individuals with a psychosocial disability.

[1] Clause 7, Schedule 1—The Statement for Australia's Carers, *Carer Recognition Act 2010*

Intersection with the Criminal Justice System

For individuals with a psychosocial disability related to a mental illness, and indeed for those with a cognitive disability, it is at best unhelpful and at worst harmful to both the individual's wellbeing and the broader community's safety to suggest that there is a bright line which distinguishes the supports required related to an individual's disability, and those related to their 'criminal behaviour'.

For example, where an individual has poor impulse control as a result of their disability, and has come into contact with the criminal justice system for behaviour related to this (such as destruction of property) it is simply not possible to distinguish the support required for the disability, and that required in response to the criminal behaviour.

For many, if they had recievd appropriate psychosocial disability support during earlier in their life they may never have come into contact with the criminal justice system. It is impossible to separate out the interacting factors of disability and disadvantage that commonly place an individual on the trajectory towards the criminal justice system.

The fact that people with mental illness and cognitive impairments are significantly over-represented in the criminal justice system is in significant part due to a failure of appropriate services and supports being available.[2]

The current stance of the NDIS in relation to this cohort therefore risks further entrenching the criminalisation of people with mental illness and cognitive impairment through the refusal to provide appropriate services. It also creates a second false 'bright line' between the needs of those who will be receiving support through the NDIS who are at risk of coming into contact with the criminal justice system, and those individuals with the same needs who have already come into contact with the criminal justice system.

In relation to this cohort (that is both those at risk and those already in contact with the criminal justice system), there are some particular considerations that need to be integrated into the NDIA's processes, namely: community safety and how to balance this in the context of individual exercising 'choice and control'.

The Commission supports the intention of the NDIS to empower individuals who live with a disability to exercise autonomy over the supports they require. However, it is necessary to recognise that there is a very small cohort where behaviour related to the individual's functional impairment arising from the disability may also pose a risk of harm to others. It is unclear how the current planning processes utilised by the NDIA allows for the identification of these issues and the extent to which considerations of community safety are then integrated into the individualised plan.

This is particularly the case where a support that may be required for the protection of the community is not one that would be chosen by the individual, or where the individual's choice of providers may not have the appropriate skill set to provide supports that are individualised but also have regard to any community safety issues.

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[2] McCausland; Baldry; Johnson; and Cohen (2013) *People with mental health disorders and cognitive impairment in the criminal justice system Cost-benefit analysis of early support and diversion*, report for the Australian Human Rights Commission https://www.humanrights.gov.au/sites/default/files/document/publication/Cost%20benefit%20analysis.pdf

It may be that for this cohort, particular approved providers need to be identified from whom the individual can choose, to ensure that appropriate and safe supports are provided. Further, there needs to be an appropriate pathway for community safety issues to be flagged during the planning process and for others to then be engaged in the planning process to ensure that these are adequately captured and addressed in the final plan.

Prisoners

For those exiting prisons, further issues arise.

The Commission understands that the NDIA currently stops any individualised package upon an individual being taken into custody, and that the NDIA will only engage in planning for community based supports once the individual has a known release date, and is within 6 months of that date. However, these positions do not recognise the reality of how the majority of prisoners enter and exit the prison system.

A high proportion of prisoners exiting prison have only been in custody for short periods of time. In December 2016, the average length of stay for those having been on remand was less than 7 weeks, while the average length of stay for sentenced prisoners was 7 months.[3] Therefore, for the majority of prisoners, there is simply not a six month period for a planning cycle to be completed. Even where an individual is sentenced, there is often only a short period between when the sentence is imposed and their final release date, once time served on remand is taken into account.

Such short periods of time in custody are sufficient to cause considerable disruption for the individual, including for their housing and employment, but insufficient for meaningful intervention. As mentioned above, we know for many their pathway into the criminal justice system has been marked by a failure in service provision. Where contact with the criminal justice system occurs, we must use this as an opportunity to redress these failures and connect people with the services they need. We can only change the trajectory of people's lives by recognising that they need support. For those who do have existing services, it is vital that the continuance of appropriate supports is assured.

Given the rapid cycling in and out of gaol many individuals experience, and the resulting instability with regard to housing and contact information, the traditional planning cycle for the NDIS is unlikely to be able to respond appropriately and in a timely manner.

The Commission therefore supports the call of the NSW Disability Council that services are 'block funded' under the NDIS to support individuals during their transition from gaol, and while more individualised plans are being developed. We know that the immediate period after release from gaol is a particularly risky time in relation to an individual's wellbeing, and the important role that throughcare and transition support provides in minimising its risk. It is vital that the NDIS is responsive to this need.

[3] New South Wales Custody Statistics Quarterly Update December 2016. Bureau of Crime Statistics and Research. http://www.bocsar.nsw.gov.au/Documents/custody/NSW_Custody_Statistics_Dec2016.pdf

Forensic patients

In NSW, forensic patients are those found unfit to stand trial and those found not guilty by reason of mental illness. Although the form of order varies for each group, central to each is that they are to be released into the community as soon as it is safe for the individual and the community for them to be released, and that they otherwise can remain detained indefinitely.

The legislative regime under which forensic patients are detained means that the requirement of the NDIA that an individual has a known release date and is within six months of that date for planning to commence is a requirement that forensic patients are, by definition, unable to meet.

For an individual to be determined safe for release, the decision maker (the Mental Health Review Tribunal) must be satisfied that there are appropriate services in place, and the model of care around the individual must also be assessed by an independent forensic psychiatrist.

The cohort of forensic patients who are likely to be eligible for the NDIS commonly have multiple diagnosis (psychosocial disability together with a cognitive impairment either due to an intellectual disability or brain injury) and complex needs in terms of behavioural supports. Previously in NSW, this group primarily received support through the Community Justice Program (CJP) run by NSW Ageing ,Disability and Home Care.

The CJP would work co-operatively with an individual's treating team in their place of detention when the treating team indicated that the individual was ready for release planning to commence. The individual, their family, the treating team, and the CJP team would then develop a plan for the model of support that would be provided in the community, including the identification of appropriate service providers.

This information could then be presented to the independent forensic psychiatrist who may make further suggestions regarding the model of care.

Finally this information could be presented to the Mental Health Review Tribunal for a determination of whether the individual could be released, and the Tribunal could attach conditions to that release.

With the transition of the CJP to the NDIS as part of the NSW contribution, there is a real risk that the above pathway to the community will no longer exist for forensic patients based on the NDIA's current stance.

The consequence of this change will be that this cohort of individuals will be detained indefinitely. This is an unacceptable outcome from the introduction of the NDIS.

As noted in the Senate Community Affairs References Committee's recent report on indefinite detention of people with cognitive and psychiatric impairment in Australia, the indefinite detention of individuals with a psychosocial disability or cognitive impairment is a serious issue requiring a range a measures across the lifespan to reduce and work towards the elimination of the practice in Australia.[4] In its report, the Committee specifically cited the uncertainty regarding the impact of the

[4] Report on indefinite detention of people with cognitive and psychiatric impairment in Australia (2016), Senate Community Affairs References Committee http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/IndefiniteDetention45/Report

introduction of the NDIS for this cohort, leading it to recommend that the Joint Standing Committee on NDIS inquire into this issue.[5]

Unfortunately, the Commission has already heard reports of the detrimental impact of the current NDIA policy in relation to forensic patients.

During the Hunter trial, forensic patients were deemed eligible and had been receiving individualised packages. An example of this was an individual who was transitioning from detention into community living and was provided with an individualised package which allowed him to engage a service provider to accompany him when he left the hospital on leave. While an element of this support was that the service provider acted as a 'supervisor' for the purpose of the relevant risk management process associated with the leave arrangements for forensic patients, crutially, the service provider supported the functional needs of the forensic patient to regain confidence in the community following a protracted period of time in detention. This included accompanying the forensic patient as he secured housing, re-established relationships with family and friends, and explore educational and employment opportunities.

Following a decision by the NDIA to apply the requirement of an individual being within six months of a known release date before they can be considered eligible for individualised packages, the support for the forensic patient has been stopped and the progress he had made in relation to re-integrating into the community has consequently suffered a substantial set back. It is now unclear what pathway exists to support this forensic patient, and others in similar circumstances, transition into the community.

There is, therefore, an urgent need for the NDIA to reconsider its stance in relation to the eligibility of forensic patients for the NDIS and to work constructively with each jurisdiction to develop pathways to support the transition of forensic patients into the community.

Other Related Matters

While the Commission welcomes the inclusion of individuals with a psychosocial disability in the NDIS, the late inclusion of this cohort has affected the promotion of the NDIS to people with a mental illness, and the understanding of how to accommodate the needs of this cohort within the NDIS.

A key aspect of this has been the assumption that the type of functional supports offered through the mental health system are similar to those offered through the disability sector. However, this is far from the reality. For example, even the language utilised by each sector has caused confusion. In mental health, a case manager works in clinical service provision and therefore is appointed during times of acute illness and generally is focused on the coordination of clinical services and assessing a person's clinical needs. This is very different from a Case Manager in a disability service, who generally helps in assisting a person access services they need to meet their needs and aspirations.

[5] Recommendation 25, 9.62, Report on indefinite detention of people with cognitive and psychiatric impairment in Australia (2016), Senate Community Affairs References Committee http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/IndefiniteDetention45/Report

They facilitate person centred planning which includes the family and person circle of support and although this may include clinical needs the focus is on longer term support.

The nature of supports is also quite different between mental health and disability. The mental health system is complex due to the need to provide support to people from one end of the spectrum of illness to the other, the need for regular adjustment of supports in response to the episodic nature of an individual's illness, and the need to co-ordinate clinical and functional supports. This is quite different from other forms of disability where an individual's needs may be more stable and/or predictable.

Due to the multiple reforms occurring simultaneously and the differences between the way the disability sector and mental health sector is organised, people with a psychosocial disability and their carers have expressed confusion and at times fear about the introduction of the NDIS. While the Commission commends the NDIA for the information created that targets people with a psychosocial disability, we believe that more education for the community is required on an ongoing basis. People with a mental illness don't often identify as 'having a disability' and ongoing community education is critical to ensuring people with psychosocial disability continue to engage with the NDIA. To achieve this, it will be critical for the NDIA to continue to work alongside peak consumer and carer organisations, as well as community managed organisation peak bodies across Australia and co-delivering education to the community.

For this to be sustainable into the future, there is a need to ensure strong advocacy organisations not only supporting individuals, but also the peak advocacy organisations. These organisations play an important role in disseminating information, but also in raising and addressing systemic issues for people with psychosocial disability. The current uncertainty around the future of current advocacy organisations has further elevated fears within the mental health community, as these organisations have been critical for ensuring a safe and responsive mental health and disability system.

Similar uncertainty faces the community managed sector which has been the traditional source of service providers in this space. The scale and pace of growth required for the NDIS to be at full scheme, together with the shift in business model required for the implementation of individualised packages is an enormous transition process for the community managed sector. While the Commission welcomes the capacity building work that has been supported by the NDIA to date, further investment of this type will be required for several years to come.