Queensland Mental Health Commission

Submission

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

Joint Standing Committee on the National Disability Insurance Scheme

February 2017

Queensland Government

Acknowledgement

We pay respect to Aboriginal and Torres Strait Islander Elders, past and present, and acknowledge the important role of Aboriginal and Torres Strait Islander people, their culture and customs across Queensland.

We also acknowledge the people living with mental health and alcohol and other drug problems, as well as those impacted by suicide, and their families, carers and support people. We can all contribute to a society that is inclusive and respectful, where everyone is treated with dignity and able to focus on wellness and recovery and have fulfilling lives.

Feedback

We value the views of our readers and invite your feedback on this report. Please contact the Queensland Mental Health Commission on telephone 1300 855 945, fax (07) 3405 9780 or via email at info@qmhc.qld.gov.au.

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Commissioner's message

The Queensland Mental Health Commission believes that the National Disability Insurance Scheme (NDIS) has the potential to bring about positive life changes for many people experiencing mental illness. However, we have significant concern that some people with mental health issues may be adversely impacted due to the pace of transition and the expectation that the NDIS can replace important 'safety net' community programs that help build independence, within a recovery framework.

The Commission acknowledges Queensland Health's recent decision to maintain funding of a range of programs during the transition period to the NDIS to ensure continuity of services.

In preparing this submission, we sought input from stakeholders, including government agencies and service providers who are preparing for or currently working with the NDIS in Queensland, as well as people living with mental illness and carers, some who have recently received an NDIS individual funding package.

This submission is structured around the terms of reference for the inquiry and makes a number of suggestions for improving the NDIS design and implementation process in order to maximize participation and effectiveness for people with psychosocial disabilities related to a mental illness.

Dr Lesley van Schoubroeck
Acting Queensland Mental Health Commissioner

Introduction

The Queensland Mental Health Commission's role is to drive on-going reform towards a more integrated, evidence-based, recovery-oriented mental health and alcohol and other drug service system. To do this we bring together experience and professional expertise by partnering with the community, government, and industry across a range of areas including health, employment, education, housing and justice.

Through these partnerships, we find solutions and guide action to improve the systems that support people with, or at higher risk of, mental illness or problematic alcohol and other drug use, people impacted by suicide, as well as their families, carers, support persons, and the Queensland community.

We are pleased that a formal avenue has been established through this Joint Standing Committee inquiry to explore and resolve the design and implementation issues that relate to the provision of services under the National Disability Insurance Scheme (NDIS) for people living with psychosocial disabilities related to a mental health condition.

The design of the NDIS has been heavily focused on people with physical disabilities. The needs of people with psychosocial disabilities and the recovery-based principles upon which their support need to be based involves a new level of complexity. People living with mental health issues who have complex needs require a multi-faceted and coordinated service system response across both health and social services. It has long been acknowledged that people with complex needs can fall through the cracks in service delivery—between national and jurisdictional service delivery, between government and non-government services, and between services delivered by different portfolio agencies. Furthermore, support needs will often vary over time and be cyclic in nature.

This submission offers some suggestions for adjusting the scheme design, better supporting the implementation process and ensuring ongoing complementary support arrangements are in place to take account of these complexities.

Response to terms of reference

Eligibility

We acknowledge that there have been efforts recently to reconcile the concept of permanent disability with the language and experience of people living with mental health conditions, particularly the need to focus on recovery and the fluctuating nature of most people's needs. We are pleased to note that there have been a number of mental health consumers and carers participating in the implementation of the Operational Access Review for Psychosocial Disability project and look forward to reviewing the new resources and amendments to NDIS processes being implemented in coming months.

We have particular concerns that, under the current access rules, a person needs to have a permanent impairment before receiving early intervention under the NDIS. Permanence (or likely permanence) may be difficult to demonstrate, particularly in a young person with an emerging mental health condition. However, without access to early interventions these people may experience a worsening of symptoms and ultimately require long-term support.

The challenge for governments is to ensure that sufficient resources are maintained to provide these supports for people who are out of scope of the NDIS.

Employing planners who are skilled in working with people living with psychosocial disability is important to ensure eligibility is fairly assessed. Some people living with a mental illness may not be able to recognise or articulate the impact of their condition on different aspects of their lives—mobility, communication, social interaction, learning, self-care and self-management. The Commission has heard reports of people with legitimate functional needs being deemed ineligible for an individual funding

package because they did not emphasise the right points to the NDIA. Planners need experience and skills in eliciting relevant information required to confirm eligibility with respect and empathy. We understand that training programs are being developed and rolled out by the NDIA to improve planners understanding of psychosocial disabilities. We urge the NDIA to continue to support staff to build deep and specialised skills around recovery based approaches to working with people living with psychosocial disabilities.

Another emerging issue is the additional impact on the health system in providing reports to support eligibility. General practitioners and other health professionals will need training and resourcing to ensure they are able to effectively document the functional needs of people with mental health conditions to support their NDIS applications. Primary Health Networks (PHN) may need to prioritise resources to support the health system in this new role.

The Commission also supports calls for NDIS planners to be able to clearly identify where behaviour is the function of a disability. For example, people living with Fetal Alcohol Spectrum Disorder (FASD) may exhibit behaviours that are related to the disability, but this may be overlooked. In this example planning teams need to be cognisant of FASD symptoms and consequent disabilities to ensure individual's eligibility will be appropriately considered.

Recommendations

- Review the early intervention pathway to ensure timely access to psychosocial support to those who may not yet display symptoms of a permanent impairment and are therefore not eligible for NDIS.
- Ensure frontline NDIA workers have specialised skills and knowledge about recovery-based approaches to working with people with psychosocial disability.
- Provide information and training to GPs and other health professionals on providing evidence of the functional impact of a psychosocial disability as well as disability resulting from FASD.

Transition of Commonwealth programs

The Commission has significant concerns about the transfer of the entire Personal Helpers and Mentors (PHaMs) to the NDIS. It is understood that many people who access this program will not be eligible for individual funding packages. These are people who need low to medium support some of the time to function in the community and may require only short term engagement. Many participants have been difficult to engage and, even if eligible, may not be willing to participate in the NDIS due to its formalised nature and the challenges associated with identifying as having a 'disability'.

While the target group for the Partners in Recovery (PIR) program is more closely aligned to those eligible for an individual funding package under the NDIS, there remain concern that a significant number of people with severe and persistent mental illness who are currently receiving support under PIR will not meet the NDIS threshold.

The Day to Day Living (D2DL) program is another successful Commonwealth program which is due to transfer to the NDIS. This program cannot be as easily funded through individualised arrangements because it is based on a peer support system, rather than a service or treatment program. Drop in centres and Clubhouses funded through D2DL provide informal group support for some of the most vulnerable in the community in a highly cost-effective way[1]. This type of service is particularly important for people who are unlikely to access formal, appointment-based supports.

[1] See, for example, strong evidence of positive outcomes from Clubhouse membership including a significant decrease in hospitalisations and reduce incarcerations. http://clubhouse-intl.org/our-impact/clubhouse-outcomes/

Block funded services like these three programs are important for situations where there is market failure, that is where consumers are unable to fully exercise choice and where markets are thin. Without a continuing safety net of block-funded services, large numbers of people with psychosocial disabilities may become more socially isolated, and more likely to end up in hospital, homeless or sadly in prison. People living in small and regional communities will be at particular risk as many service providers will not have the capacity to maintain a presence in these communities to service only small populations of higher needs clients.

Each of these functions could reasonably be funded under the Information, Linkages and Coordination (ILC) element of the NDIS, if sufficient resources were made available.

Recommendations

- Consider the NDIS as a supplement to, rather than a replacement for, existing Commonwealth funded community mental health services.
- Continue to fund PHaMS-type services through block funding arrangements, possibly through the ILC component of the NDIS, for people who do not meet the eligibility criteria for an NDIS individual funding package to continue to receive required functional supports.
- Ensure the functions of PIR support facilitators are available for those that do not meet the eligibility criteria for an individual funding package.
- Ensure continued funding for informal drop-in services, including clubhouses, possibly through the ILC component of the NDIS, to provide an avenue for some of the most vulnerable in our community to access support.

Transition of State programs

Queensland Health has advised that it supports the continued delivery of support services to people living with mental illness; is committed to maintaining a portion of the community managed mental health state investment and will work with the sector throughout the transition of NDIS.

Nevertheless, there continue to be concerns within the community mental health sector about the transition process, particularly the impact of the likely break-down in partnerships between local Hospital and Health Services, community services and the Department of Housing that have been established under the successful Housing and Support Program (HASP). HASP provides a coordinated framework of social housing and support to people who are residing in or are frequently admitted to mental health facilities and are homeless or at risk of homelessness.

Without HASP, participants and their supporters may need to decide for themselves where they will live and how they will be supported. It is estimated that about a third of people previously eligible for HASP will be at risk of dropping out of the service system during the transition to the NDIS.

Recommendations

- Build strong connections between health, community services, housing services and NDIA support coordinators to maintain full wrap-around services for people exiting treatment who are at risk of homelessness.

Information, linkages and capacity building framework

The focus of the ILC for people living with mental illness needs to be one that provides supports for people who need low intensity or episodic supports that are not easily delivered through individual funding packages and for people who need recovery-focused early intervention support to ensure their condition will not deteriorate to a point where they may need access to an individual funding package. Carer

support is also an important element to include in the ILC for those carers who do not receive support under individual funding packages.

ILC-type activities supporting people to access mainstream services and making communities more accessible are critical to ensure that people living with mental illness are able to function in the community, given that only about 12 per cent will be eligible for packages. The Commonwealth programs which are being transferred to the NDIS, particularly PHaMS, PIR and D2DL, currently provide many of the individual capability and community capacity building services identified in the ILC for people who will not have access to an NDIS plan.

We note that funding periods for ILC grants will be variable. 'Safety-net' services funded under ILC arrangements, for those individuals who are not eligible for an individual funding package, need to be funded over an extended period so that there is some stability for service-users and service providers have the time and confidence to plan effectively and innovate.

Local Area Coordination will need to maintain a strong focus on the needs of people living with a psychosocial disability, their families and carers in order that people do not fall through the cracks. The Commission is concerned that the decision to give the Local Area Coordinator (LAC) planning functions may impact on their capacity to undertake key community inclusion functions, particularly during the transition period when large numbers of plans are being processed. LACs will have a particularly important, and potentially resource intensive, role in providing outreach to many people with mental health conditions who are not currently connected to services, including potential participants from Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD) and homeless populations (see 'outreach to identify potential NDIS participants' section below).

Recommendations

- Review the ILC budget to ensure it is sufficient to provide capability building activities needed for the 78 per cent of people with psychosocial disability who will not be eligible for an individual funding package.
- Provide longer-term contracts for 'safety-net' services provided under the ILC element.
- Ensure the LAC planning functions are not taking focus and resources away from important community capacity building functions and outreach.

Planning process

Many people living with mental illness experience problems processing and remembering information. Some people are unaware of the impact of their illness and the supports they need and some may not give permission for a carer or support person to be involved in planning conversations, particularly if they are unwell. All this makes the planning process more complex.

Undertaking planning conversations over the phone is generally not appropriate for this group due to the complexity of the communications and support needs. All participants with psychosocial disability should have a face to face planning meeting as a matter of course.

Planners need to have specialised skills and experience in working with people with psychosocial disability. The Commission has heard that skills of planners working with participants with psychosocial disabilities and the quality of the plans are extremely variable. The structure of some plans has a perverse effect of reducing people's independence and creating service dependence. Planners must also recognise the episodic nature of living with mental illness that may include periods of hospitalisation. Individual plans and packages need to be flexible and responsive to accommodate changing needs. We understand that in some trial sites specialised NDIA mental health planning teams were established and recommend this approach be broadly adopted within frontline NDIA and LAC teams.

When families and carers are excluded from planning conversations, important information may not be relayed and plans may not reflect true needs. We are pleased that there is an option for carers needs to be considered through completion of a Carer Statement in which they can discuss their own goals and the sustainability of the care that they provide and that this can be discussed in a separate conversation with the carer. Carers need to be informed about this option as a matter of course.

We note the Joint Standing Committee has previously recommended a 'cooling off' period after the plan is drawn up, similar to other insurance practices. This would give participants time to discuss the plan with family, friends, peer support or seek professional advice before signing off. We support processes that encourage participants to reflect on and discuss their plans before they are approved, particularly given that the people with a mental health condition tend to have fluctuating impairments and support needs. The timing of the planning meeting may not be optimal, and this could affect the quality of the plan.

It is also important that participants are clear about when to expect their plan to arrive and what to do with it when it does arrive. Sometimes the plan document arrives in the mail several weeks after the meeting. It would benefit many participants with a mental health condition if the planner (NDIA or LAC) could actively follow-up with participants immediately after they receive their plan to ensure they are well informed about what the document means and the next steps for accessing support.

Recommendations

- Schedule face to face rather than phone planning meetings with applicants with psychosocial disabilities due to a mental health condition.
- Establish highly trained teams of frontline mental health specialist planners within the NDIA and LACs.
- Consider processes to encourage participants not to sign off their plan at their planning meeting, but take time to reflect on the content and discuss it with supporters before it is approved.
- Follow up with participants after they receive their plan to reiterate the purpose and next steps for receiving support.

Spending in line with projections

To keep spending in line with projections adequate funding needs to be made available for early intervention and low-medium support services under the ILC component of the NDIS. This will reduce demand for individual funding packages, providing a more cost-effective approach.

Also, a more consistent approach to reasonable and necessary supports for psychosocial disability is needed, as well as processes for responding to variations in support needs. Planners need skills in working with people with a mental health condition to understand what services are required at what times in order to build independence and boost recovery. This will also help ensure spending on plans is targeted, adequate, but not excessive.

The Commission has concerns that the NDIA has underestimated the cost of providing core support to a person with a mental health condition. In the current Price Guide assistance with core supports and community access is priced at $42.79 an hour. Services advise that these roles are currently priced at about $65 per hour due to the specialist skills and knowledge required to work with people with a mental health condition. Initial savings may result in longer term costs if the quality of support deteriorates and/or there is an undersupply in the workforce.

Recommendations

- Develop a consistent approach to reasonable and necessary supports for psychosocial disability and processes for responding to variations in support needs.
- Review the NDIS Price Guide to ensure that core support for people with mental health condition is appropriately priced.

Outreach to identify potential NDIS participants

Many people living with a mental health condition have negative associations with the language of disability and impairment, and some have limited insight into the assistance they require. It is estimated that up to half of people with severe mental illness are not engaged with the 'system' at all,[2] let alone being familiar with the concepts and practice related to individualised funding and self-directed support. People living with a mental illness may not be comfortable engaging with formal services or with 'government', therefore the NDIA must make itself relevant and engaging to potentially eligible participants.

Importantly, in many cases it will not be the person with the lived experience doing the 'help-seeking', therefore outreach approaches will need to be broad-based. The NDIA and LACs will require skilled, proactive and flexible approaches to engaging with potential participants and their support systems to ensure those with the highest support needs are identified and offered the opportunity to be involved in the scheme. Particular efforts will be needed to engage with Aboriginal and Torres Strait Islander peoples, through Indigenous organisations, with people with culturally and linguistically diverse backgrounds, through migrant and refugee groups, and with lesbian, gay, bisexual, transgender, intersex and questioning (LGBTIQ) people through social and support groups.

Relationship development will be critical to build trust. Existing agencies with demonstrated expertise in undertaking outreach to the various different client groups might often be most suitable to undertake this work. Outreach and engagement will need a long-term investment. Given the significant access barriers, it is likely to take several years before the NDIS is a broadly accepted entry-point to services amongst people with a mental health condition.

Recommendations

- Implement broad-based outreach approaches led by agencies that have experience and cultural competence to engage with the various groups of people with a mental health condition and their families, carers and supporters.

Forensic services

Many people will face challenges transitioning from inpatient hospital based services to community based treatment and support. This may be particularly difficult for people exiting long-term inpatient forensic mental health services or forensic disability services. For the most part, there should be no difference between how the NDIS will be available in these circumstances to support the transition. Key agencies (health, justice and the NDIA) will need to work together to maximise the interface between treatment and supports.

Transition plans for individuals under an involuntary treatment or forensic order need to be based on an outcome-oriented process that promotes the transition of the person from an authorised facility (such as a mental health ward or forensic disability service) to living in community. The transition plan would ideally require assessment of eligibility for supports under the NDIS to enable the earliest possible transition to supported community-based arrangements.

The ILC element of the NDIS could also assist in strengthening the transition of people from detention to community living through, for example, assisting people within this cohort to engage with often difficult-to-locate mainstream services and resources and strengthening an individual's ability to interact successfully with the broader community.

[2] Mental Illness Fellowship of Australia (2016) "NDIS and people affected by mental illness"

Recommendations:

- Include an automatic NDIS assessment as part of transition plans from inpatient forensic mental health services or forensic disability services.
- Consider funding within the ILC to strengthen the transition of people from detention to community living.

Quality and safety

The Commission commends NDIA on the development of the NDIS Quality and Safeguarding Framework but seeks to ensure that this Framework is reviewed through the lens of the National Standards in Mental Health Services. As work by the Australian Commission on Safety and Quality in Health Care has demonstrated, there are some unique features within the safety and quality framework for mental health services that do not have the same priority within the more general *National Safety and Quality Health Service Standards*. Furthermore, experience in Queensland has demonstrated that complaints mechanisms, particularly for people on involuntary treatment orders, can be quite complex. It is therefore essential that the interface of Commonwealth based complaints mechanisms for NDIS with existing mechanisms individuals may be accessing is clearly articulated.

Recommendations:

- Review the NDIS Quality and Safeguarding Framework from the perspective of people with mental illness, including the interface of the complaints mechanisms with state based complaints management systems.

Conclusion

The Commission acknowledges the work underway to improve the NDIS design and implementation to better accommodate people with a mental health condition. Many of the challenges are 'teething issues' which, with adequate attention, can be resolved over the NDIS transition period.

While we applaud the efforts to meet transition targets, a strong focus on getting the foundations right is also required, including improving the skills of planners and the processes they use in working with people with psychosocial disability. We also urge the Joint Standing Committee to recommend a much better resourced ILC component in order to provide a safety-net for the significant number of people with psychosocial disabilities related to a mental health condition who will not be eligible for an individual funding package and those who will continue to experience barriers in engaging with the NDIS.

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