Submission

Joint Standing Committee on the NDIS: The Provision of Services under the NDIS for people with psychosocial disabilities related to mental health conditions

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Introduction

Queensland Alliance for Mental Health (QAMH) is the peak body representing the community mental health sector in Queensland. Representing and supporting organisations, services and groups that meet the needs of people who experience mental health issues, QAMH leads the community mental health sector through advocacy, capacity building and leadership development with a focus on ensuring a place for community mental health in the healthcare continuum. QAMH comes together with the eight state and territory peak community mental health organisations as a member of Community Mental Health Australia (CMHA) to create a national, unified voice which represents around 800 community-based, non-government organisations that work with people with mental health issues and their families and friends.

QAMH has coordinated and chaired the Queensland Transition to NDIS for Mental Health Strategic Forum (QTN Forum) since September 2015. This forum provides a mechanism to discuss the specific issues for people who live with a mental illness, community mental health service providers, representative bodies and state and commonwealth governments in the plan for roll-out of the National Disability Insurance Scheme (NDIS) in Queensland. The QTN Forum, the only state forum of its kind nationally which has a focus on psychosocial disability, aims to develop a shared vision for a future service system once NDIS is implemented. The members work closely together to consider issues and plan for the ongoing transition of the NDIS in Queensland.

QAMH would like to thank the Joint Standing Committee for the work that it has committed to undertake as part of this Inquiry, and for providing QAMH and its members and stakeholders with the opportunity to make a submission. QAMH acknowledges the contributions from member organisations, alliances and consortia from across Queensland whose information has informed the development of this submission. QAMH welcomes the opportunity to discuss any aspect of this submission in more detail with the Joint Committee at any time.

Whilst QAMH is committed to the NDIS and positive outcomes for people living with a mental illness, their families and friends, it is concerned that mental health issues cannot be simply made to fit into a system designed to provide disability support. A failure to recognise the complexities and issues specific to psychosocial disability, and to ensure that adequate funding is made available through appropriate mechanisms, may result in less than optimal outcomes for people with mental health issues, their friends and families. This will also place additional pressure on the health and social services systems.

Further, it is vital to ensure that the recovery focus of community mental health services continues, and that a situation is not created where some people receive a high level of support but others, who are unable to access the system because of their circumstances, do not. People living with mental health issues must have their psychosocial needs met regardless of whether they are eligible or ineligible for the NDIS.

Response to the Terms of Reference

1.a The eligibility criteria for the NDIS for people with a psychosocial disability

Clarification of the eligibility criteria as well as the NDIA assessment processes

QAMH supports the recommendation from the National Mental Health Commission (NMHC) Review of Programs and Services to "urgently clarify the eligibility criteria for access to the National Disability Insurance Scheme (NDIS) for people with a disability arising from mental illness".'[1] A lack of clarity regarding eligibility, particularly in relation to some diagnoses, coupled with difficulties for many people to provide evidence of eligibility such as medical diagnosis and assessment in a timely and cost effective manner is proving to be a significant access barrier for some people with psychosocial disability. Difficulties around obtaining evidence can include, in some instances, long waiting lists for psychiatry and neurology appointments.

For many people, providing evidence of permanence of psychosocial disability is problematic with some people not wanting to be labelled as having a mental health issue. More generally, community mental health organisations report that it can be quite difficult to engage with some clients when they are unwell. This raises issues for many service providers around appropriate and ethical considerations for assisting people to gather evidence of eligibility, where there are no family or friends to act on their behalf and independent advocacy is required.

Community mental health organisations in areas in Queensland where the rollout has commenced, report inconsistencies in decisions made by National Disability Insurance Agency (NDIA) around eligibility and dollars included in NDIS packages. The reasons why some people with mental health issues have been found to be ineligible, or why packages can be for such varied amounts is not clear to either participants or service providers and leaves people increasingly frustrated with the lack of clarity around the NDIA assessment processes. A lack of understanding from NDIA assessors about psychosocial disability has also created issues in the community. Some people currently receiving supports in the community will receive a lower level of support post-NDIS.

Information and upskilling for General Practitioners (GPs) and other community clinical service providers on the NDIS and their role in providing evidence of eligibility

In some areas of Queensland, community mental health organisations report that a lack of knowledge of the NDIS amongst GPs and other clinical service providers has resulted in major barriers to access an NDIS package. Many people report that their GPs have little idea of what their patient's daily life is like, so feel they are not in a position to comment on this when preparing documents for NDIS assessment. This is illustrated in the following quote from a Partners in Recovery participant in Queensland.

> *"You can't see a psychosocial disability. GPs don't understand mental illness. In the past 10 years I've been to so many doctors and they just dismissed me because I am just a junky…..getting help is so hard."*

The development of a workforce strategy is required to support both the mental health workforce and primary health workers, especially GPs, to upskill them on mental health issues related to a psychosocial disability as well as their role in NDIS and how they can best support their patients through this time of transition.

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[1] National Mental Health Commission, 2014: The National Review of Mental Health Programmes and Services. Sydney: NMHC

Ensuring face-to-face assessments are offered to people with psychosocial disability

These issues are further exacerbated by the recent move away from face-to-face assessments by the NDIA which has had a significant impact on outcomes for people with a psychosocial disability. Whilst QAMH recognises the time intensive nature of face-to-face assessments and planning, for people with psychosocial disability, a telephone assessment creates significant difficulties for communicating or assessing their level of need.

Consideration needs to be given to the ability of the NDIA assessor to be able to build and create a trusted relationship with a participant with psychosocial disability. For many people with mental health issues, trust can take time to develop and is very difficult to do via the telephone. This is particularly relevant for many people from culturally and linguistically diverse backgrounds (CALD) and for people who are new arrivals to Australia. Often, due to their circumstances, it can take significant time to build trust and there is potential to re-traumatise and reduce people's health and wellbeing if this process is not undertaken appropriately. For many people they will never disclose their mental illness.

Consideration of the episodic nature of mental illness must also be taken into account during the assessment process for people with a psychosocial disability. An assessment and planning meeting over the telephone restricts an adequate assessment of the person's needs and circumstances.

For people from CALD backgrounds, access to appropriate interpreting services and to an assessor that has cultural competence will be critical to ensuring that people are supported during the assessment process. Assessment via the telephone for many people from CALD communities will simply not be appropriate.

Many people are being contacted by phone by an NDIA representative without being informed that the conversation is an official planning meeting. This often leaves people unprepared and unsupported by family, friends or service providers during the assessment process and leads to poorer outcomes for people in terms of eligibility or receiving an appropriate NDIS package.

Clarification of the provision of support for carers

There is concern about the proportion of funding available through the NDIS to appropriately support carers given that a significant proportion of Commonwealth funding for carer programs has been committed to the NDIS. Support for carers should not be tied to a person's NDIS package as, in the case of many people with a psychosocial disability, they may not recognise their need for a carer or recognise that they have a carer. Findings of the September 2016 Intermediate Report of the Evaluation of the NDIS by the National Institute of Labour Studies, Flinders University found that an unintended consequence since the NDIS roll-out was that support for carers both inside and outside of the NDIS had diminished.[2]

Clarification of the provision of transport within NDIS packages

No funding or an inadequate amount of funding has been included in NDIS packages for people with psychosocial disability to use for transport. This places many people with mental health issues in a disadvantaged positon and has financial implications for individuals with less funded supports. It

[2] Mavromaras, K., Moskos, M. and Mahuteau, S. (2016) Evaluation of the NDIS, Intermediate Report, September 2016. Adelaide: National Institute of Labour Studies, Flinders University.

requires them to find additional money to address the shortfall, increases social isolation of those who can't afford the additional expense or increases the financial burden on service providers who provide this service unfunded. This issue may be further exacerbated as the NDIS continues to roll out in more rural and remote regions of Queensland.

1.b The transition to the NDIS of all current long and short term mental health Commonwealth Government funded services, including the Personal Helpers and Mentors services (PHaMs) and Partners in Recovery (PIR) programs, and in particular;

i. whether these services will continue to be provided for people deemed ineligible for the NDIS;

Continuity of service

There are significant concerns about continuity of service for people currently receiving support from the Department of Health (DoH) and the Department of Social Services (DSS) through programs including Partners in Recovery (PIR), Day to Day Living (D2DL) and Personal Helpers and Mentors (PhaMs). In Queensland, it is currently unclear how many people will be found to be ineligible for an NDIS package, for some of the reasons outlined in section 1.a of this submission. Whilst many of these people, currently receiving assistance from these programs, will transition to the NDIS, outcomes from other States indicate that some people may fall through the gaps. QAMH has been pleased that funding for some of these programs has been extended in Queensland to ensure support for people during this transition phase, however, should funding be withdrawn, these services will cease and people with mental health issues who require support in the community will be left without supports.

If this gap is not addressed, the impact will be felt in Queensland by the state mental health and other systems and be evidenced by an increase in hospital admissions, reports of self-harm and suicide.

Continued access to a Commonwealth government funded, flexible low barrier to entry service that sits outside of the NDIS for people who need ongoing community and coordination support.

The Commonwealth programs from which the funding is being removed and transferred to the NDIS, including PIR, D2DL and PHaMs, have been largely successful in achieving their aims. Consideration will need to be given to how people living with mental health issues who are unable to meet eligibility requirements for the NDIS for a variety of reasons are provided continuity of support. Continuity of support is necessary for recovery and its importance to people with a psychosocial disability is illustrated in the following quotes from PIR participants:

> *"They miss the point of continuity of care. If you have been seeing the same Doctor for 10 years in Brisbane, you want to see the same one."*

> *"For us a month or two-months' worth of services is a big deal."*

1.c The transition to the NDIS of all current long and short term mental health state and territory government funded services, and in particular;

i. whether these services will continue to be provided for people deemed ineligible for the NDIS;

QAMH is also concerned about outcomes for people with mental health issues currently supported through the Queensland Health funded Housing and Support Program (HASP) which has been identified as a defined program by the NDIA. Issues around the transfer of data to the NDIA has meant that approximately half of these clients are required to go through the application process as if they were a new participant. Many of the community mental health organisations that receive HASP funding and currently support these clients were only made aware of this issue in recent weeks.

In addition, concerns have been raised by community mental health organisations on behalf of HASP clients reporting that NDIA assessors have not recognised HASP as a defined program and requested evidence of disability to support their applications. This has resulted in many of these clients receiving a reduction in support. A number of appeals against this outcome are being currently lodged.

1.d The scope and level of funding for mental health services under the Information, Linkages and Capacity building framework;

No comments.

1.e The planning process for people with a psychosocial disability, and the role of primary health networks in that process;

In Queensland, planning for people with a psychosocial disability who are currently receiving services is undertaken by their service providers, including working with people through the appeals process, where applicable. This includes the community mental health organisations who are members of PIR consortia including many Primary Health Networks (PHNs). The North Brisbane PIR NDIS readiness project identified the need for policy makers to focus on resourcing flexibility and support in pre-planning, planning and review processes. The participant group often requires significant time to trust the people working with them and they frequently experience changes in their circumstances due to the episodic nature of mental health issues.

In some areas of Queensland, some PHNs have limited knowledge of NDIS. As previously discussed, community mental health organisations in some regions have identified a gap in knowledge and engagement by GPs and other clinical service providers that can be frustrating for people requiring evidence of psychosocial disability. The role of the PHNs in terms of NDIS seems at this point unclear.

The planning process needs to be flexible and responsive in order to be able to adequately support people in the event of a crises by making funds quickly available and accessible. Not all community mental health organisations will be able to manage additional expenses such as crisis accommodation until participant funds are received. An inability to access this funding when needed may result in an increased workload for emergency services personnel and Emergency Departments and may result in increased hospital admissions.

1.f Whether spending on services for people with a psychosocial disability is in line with projections;

There are significant concerns with the overall transparency of how funding is being provided by governments at the federal, state and territory level, including the general lack of information being made available by governments. This is creating difficulties in determining if spending for people with psychosocial disability is keeping in line with projections.

CMHA wrote to all state and territory health or mental health ministers on 22 December 2016 requesting the following information by 31 January 2017:

- a total figure of the annual committed contribution to the NDIS from existing mental health funds;
- a total figure of the committed funding to community managed mental health services at the year of full transition of psychosocial disability to the NDIS in your jurisdiction; and
- a breakdown of the community managed mental health sector funding by service type (as per the NGOE Data Set Specifications or the nearest approximation).

At the time of finalising this submission, this information had not been provided.

1.g The role and extent of outreach services to identify potential NDIS participants with a psychosocial disability;

There is concern about engagement with and access to the NDIS for those people who experience social and geographic isolation in rural and remote regions of Queensland. Feedback from community mental health organisations is that these people are often hard to reach and generally not engaged with services due to lack of knowledge of the availability of services and supports. For many of these people experiencing mental health issues, access to appropriate and understandable information is challenging. In some rural and remote regions in Queensland, there are also concerns that there won't be adequate NDIS registered services available for people to purchase the supports and services that they need.

Experiences of the NDIS rollout on Palm Island and in some other Aboriginal and Torres Strait Islander communities have uncovered the importance of working with a community to identify tailored ways in which to support the transition utilising an outreach model. Identifying activities appropriate to the community, ensuring appropriate methods for measuring outcomes are employed, appropriately resourcing and acknowledging the importance of family supports are all important aspects of outreach that should be considered for many communities. This includes CALD communities as well as Aboriginal and Torres Strait Islander communities. The one size fits all approach to the delivery of NDIS information has not been particularly effective in terms of assisting the NDIA to reach their targets. A more tailored, thoughtful and patient approach, working with each community and drawing on their own strengths could have proved to me more effective in supporting people to engage with the NDIS.

1.h The provision, and continuation of services for NDIS participants in receipt of forensic disability services;

No comments.

1.i Any related matter.

Workforce

Half of the respondents to the PIR Support Facilitators survey, undertaken by the Darling Downs Partners in Recovery Consortium, indicated that their biggest personal concern during the transition to NDIS was workforce uncertainty. QAMH is supportive of the development of a workforce strategy to provide particular assistance to the peer workforce (both paid and volunteer), including assisting the workforce to prepare for and transition to the NDIS. This would build the capacity of this workforce to assist people with mental health issues and their friends and families to access the scheme productively. Along with a strategy for peer workers, key areas of need include Aboriginal and Torres Strait Islander people, CALD communities and rural and remote regions and should also be considered as a focus and part of the strategy.

Pricing

Feedback from the community mental health sector in Queensland and elsewhere across the country, is that the NDIS pricing is not sufficient to enable organisations to purchase a suitably skilled and qualified workforce to engage in complex cognitive behavioural interventions as well as the provision of direct personal care required for NDIS participants with a psychosocial disability. Whilst QAMH recognises that the NDIA does not officially set mental health sector workers' wages, it is clear that this costing and pricing structure does have a significant influence over the remuneration that mental health organisations are able to pay their employees.

It is understood that in the Australian Capital Territory there have been difficulties in sustaining adequate and quality staff due to changes in the award requirements in order to meet the lower NDIS prices. This has already been felt in advance of the roll out in Queensland as, simultaneously, staff members explore alternative options of employment and organisations reduce their workforce in the early transition phase. This leaves many organisations with a workforce of unqualified staff and unable to meet the needs of NDIS participants. This impact of the NDIS pricing structure and its relationship to qualified mental health staffing is a concern to QAMH.

Quality and safety

It is vital that NDIS Quality and Safeguarding Framework develops quality assurance processes specifically for psychosocial services in order to maintain and support the community mental health sector workforce and ensure the current quality of service continues through the transition to the NDIS. The initial findings of reports for psychosocial disability in terms of the services people with a mental health issues are receiving and the impact this is having on their life, are a cause for concern. Issues around quality are a central aspect which must be addressed. Safeguards are necessary in order to minimise an individual's risk of exploitation by organisations who are ill-equipped and inexperienced in working with people with mental health issues. A quality and safety framework should include responses to people from CALD backgrounds as well as Aboriginal and Torres Strait Islander people, including ensuring that organisations that provide these services are culturally responsible.

Specific issues for CALD communities and new arrivals to Australia

Access to appropriate information

QAMH is concerned about the low engagement and uptake of NDIS for people in CALD communities in Queensland and elsewhere across the country. Accurate data is not currently available as NDIA data collection poses issues for accurately identifying people from CALD backgrounds. QAMH would recommend that collecting data for country of birth, ethnicity and language spoken is required to accurately portray a picture of people from CALD communities.

At a general level, access to information about the NDIS for CALD communities has been limited. Whilst there have been some resources made available in other languages, the terminology used in these resources is often disempowering or culturally inappropriate for many CALD people.

CALD Strategy and Action Plan

There appears to be a perception from within the CALD community that there is a lack of interest from NDIA to engage with these communities, demonstrated by the delays in finalising the CALD Strategy and Action Plan as well as a lack of demonstrated interest in engagement with communities. Finalisation of this plan is required and an engagement strategy which includes a genuine, culturally appropriate approach to conversations with CALD communities about mental health issues, the concept of living a good life and how the NDIS can facilitate this for people. QAMH is concerned that a significant proportion of people from CALD communities will not be able to self-advocate and will, therefore, need advocacy support as part of their transition to the NDIS. The issue of who will fund this type of support for people who require advocacy needs to be addressed.

Conclusion

QAMH is very concerned at findings from the September 2016 Intermediate Report of the Evaluation of the NDIS by the National Institute of Labour Studies, Flinders University that found that while overall the NDIS trials had led to increased supports and improved outcomes, qualitative reports showed that a particular group of people experienced poorer outcomes and lower levels of service. These were people unable to self-advocate, specifically people with psychosocial disability. Both the qualitative and quantitative data showed that people with mental health and psychosocial disability were more likely to report less control and choice since becoming NDIS participants.[3]

The Flinders University report also collected quantitative information on three measures of wellbeing: (1) psychological wellbeing; (2) Personal Wellbeing Index; and (3) sense of social connection. On all three measures NDIS participants with a mental illness or psychosocial disability recorded a mean measure of wellbeing significantly lower than for other disability groups.[4]

The NDIS readiness project undertaken by North Brisbane PIR highlighted the vulnerabilities of people with psychosocial disability and their entry into the NDIS. These people frequently experience social isolation, stigma, misunderstanding and disempowerment and require education, clear communication, understanding, skill, and time to engage with the NDIS. In addition, these people can have very specific and changeable individual needs, which require flexibility in the provision of their support.

[3] Mavromaras, K., Moskos, M. and Mahuteau, S. (2016) Evaluation of the NDIS, Intermediate Report, September 2016. Adelaide: National Institute of Labour Studies, Flinders University.

[4] Ibid

Recommendations

QAMH sees that there are potentially three options for the Joint Standing Committee to consider regarding the provision of services under the NDIS for people with psychosocial disability related to a mental health condition. These are:

1. Remove psychosocial disability from the scope of the NDIS and deliver community mental health services and supports via a mix of commonwealth and state funded programs.

Withdrawing funding for psychosocial disability from the NDIS and dispersing these funds back to the states and territories would allow for the development of a more regional and considered approach to the disbursement of funds to support people with a mental health issue. This may enable the commonwealth government to fix the overall economic costs by providing block funding to support more people for shorter periods to better meet the episodic nature of psychosocial disability.

2. Psychosocial disability services continue to be delivered as part of the NDIS however, operational guidelines specific for psychosocial disability are developed and implemented.

The development of Operational Guidelines specifically for psychosocial disability which address the issues raised in submissions to this Inquiry, and include a review of assessment protocols, would be a useful approach to address the significant shortfalls to date of trying to fit mental health issues into a disability framework. A consultative approach which includes people with a psychosocial disability, families and friends as well as community mental health organisations would be required for the appropriate development of these guidelines.

3. Psychosocial services continue to be delivered as part of the NDIS and in addition, the Commonwealth and state/territory governments fund a flexible low barrier to entry service that sits outside of the NDIS for people who are found to be ineligible who require ongoing community and coordination support.

Given the concerns raised to date about those people with psychosocial disability that will either be ineligible for an NDIS package or be unable to access the NDIS for reasons raised in this submission, maintaining current funded program such as PIR, PHaMS, D2DL and Mental Health Carers: Respite Support Program will ensure that people do not slip through the gaps and ensures continuity of service for the most disadvantaged and hard to reach people in the community.