



Submission to the National Disability Scheme Joint Taskforce Consultation Regulation Impact Statement National Disability Insurance Scheme, February 2013.

Introduction

The Mental Health Council of Australia (MHCA) is the peak, national organisation representing and promoting the interests of the Australian non-government mental health sector. The membership of the MHCA includes national organisations of mental health services, consumers, carers, special needs groups, clinical service providers, community and private mental health service providers, national research institutions and state/territory peak bodies.

The MHCA is committed to the development of program funding for people with a disability to support the human rights outlined in the United Nations Convention on the Rights of Persons with Disabilities¹ and to maximise options for choice and control over those supports. We are pleased to be able to comment on the *National Disability Joint Taskforce COAG Regulation Impact Statement on the National Disability Insurance Scheme (NDIS) Bill*.

The Regulation Impact Statement (RIS) is a key document in the development of the NDIS. It seeks to consider the impact of four Options for the implementation of the NDIS Launch and, if introduced nationally, in the longer term. Input is sought on the market, consumers and carers, providers, state, territory and Australian Governments, the community and distribution of services.

Because these issues are of significant importance to the operation of the NDIS, the RIS needs to be made accessible to a wide audience for consideration. However, opportunity for input was not well advertised on the NDIS website and mental health sector stakeholders were not informed about the COAG consultation process.

The MHCA is also concerned that the RIS already reflects little consideration of the NDIS impact on disability services for people with psychosocial disability related to mental illness. For example the RIS considers the extent to which individualised support is a feature of disability services throughout Australia but does not acknowledge that individualised support has not been widely used for service delivery in the community managed mental health sector. Further it makes reference to the Disability Services Standards but not the National Mental Health Standards.

Without the satisfactory input of mental health consumers and carers and the community managed mental health sector, it is difficult to determine whether the

¹ United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. United Nations, Geneva.

specific elements of each Option are suitable or unsuitable for implementation. We propose that further engagement with the mental health sector will be needed to satisfactorily complete the RIS.

The following is a summary of the challenges involved in determining possible impacts of the proposed Options and what issues need to be further considered for effective NDIS implementation, both in the Launch sites and if introduced nationally.

Impact on the community managed mental health sector and other mental health and disability service arrangements

Some state and territory, non-government, mental-health-peak organisations report not yet being engaged with their local Launch sites. This issue is of significant concern to the MHCA as the inclusion of these groups in the Launch preparations would seem to be a key step in involving people with psychosocial disability in the NDIS.

This lack of engagement makes it very difficult to anticipate the regulatory impact of the NDIS Launch on these organisations, which play a critical role in the lives of people with a psychosocial disability. For example there is currently not enough available information to determine the impact on:

- those mental health consumers with psychosocial disability who may be eligible for support but who do not wish to acknowledge their disability or associate themselves with the NDIS;
- those eligible participants who have traditionally never received disability supports and how the NDIS will reach out to them.

Another impact of the implementation of the NDIS Launch will be the challenges in managing expectations of policy makers, legislators and sector employees between the disability and mental health sectors. For example, because of the lack of historical linkages between the disability and mental health sectors there are probably differences in understanding about the way services should be provided to people with psychosocial disability in both sectors. The RIS would be a good place to highlight these differences and the potential impact on the implementation of the NDIS.

This situation is likely to be thrown into sharp relief with the implementation of the Australian Government Partners in Recovery Program being implemented by the Department of Health and Ageing.² This program aims to coordinate support and flexible funding for people with severe and persistent mental illness and complex needs. The program will target supports to clinical and other services from a range of agencies. At the very least Partners in Recovery Support Facilitators need to build strong links with one or more NDIS Local Area Coordinators to ensure that services are comprehensive and streamlined.

Recommendations

² See Department of Health and Ageing website:
<http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pir>.

1. As a matter of urgency, the National Disability Scheme Joint Taskforce should investigate how well mental health consumers and carers and the community managed mental health sector are being included in the implementation of the NDIS Launch in each relevant state and territory.
2. The RIS should consider the impact of the proposed NDIS Options on the disability supports currently being provided to mental health consumers with a psychosocial disability, including impacts on:
 - community managed mental health organisations and how they will function under the NDIS;
 - disability related mental health initiatives such as the Australian Government Partners in Recovery Program.

The impact on service quality

The RIS is very 'black and white' in its assumptions about services for people with disabilities. From the RIS it could be concluded that:

- a. There is a direct causal relationship between regulation and lack of choice/quality in services for people with disabilities.
- b. The current regulatory framework for disability services is the reason for the lack of choice and quality.
- c. Establishing a market based system for disability services will result in more choice and quality in disability services.
- d. Consumer choice will successfully regulate quality and demand in a market based system of disability service provision.

The further somewhat contradictory assumption is also made:

- e. That the current regimen of government regulation mechanisms for disability services is the only method (or at least the most successful apart from a market based system) for regulating the quality of disability services.

These first four themes are all somewhat true but also convey some false implications. The complexity around the way government regulation, market based systems, and consumer choice interact needs to be explored in more detail and appropriate conclusions drawn across the Options offered. The terms 'market based system' and 'regulation' also need to be defined within the context of the paper.

While the current regulatory framework is probably a major factor in eliminating choice it is not the only factor. Other major factors include cost of services, lack of service funding, deficient quality assurance systems and lack of incentive for change.

Despite these other factors, the RIS also proposes that current regulatory processes ("quality assurance, service standards and reporting requirements")³ will be used to moderate the quality of services under Options 2, 3 and 4. Yet current regulatory processes are probably only moderately successful at maintaining quality, and it

³ National Disability Insurance Scheme Joint Taskforce. (2012). *COAG Consultation Regulation Impact Statement, National Disability Insurance Scheme, December 2012*. National Disability Insurance Scheme Joint Taskforce, Canberra.

must be acknowledged that they do not necessarily guard against regular and significant failures in quality and safety in disability service systems.

The RIS needs to acknowledge that:

- current regulatory processes governing quality need improvement to raise the standard of service provision
- market forces are not necessarily good at regulating the quality of services.

These factors should both be described as key risk management issues under the Options proposed.

Therefore the proposed Options should also include alternative mechanisms for regulating the quality of disability services, and the RIS needs to consider the operational implications and costs of these. These should include provision for:

- The education of NDIS participants to be informed consumers. This would not equate to leaving it up to consumers to determine the quality of services as may be done in a market based system (although this option should be offered as a choice if consumers demand it) but to complement current quality processes and as a capacity building element of consumer participation in the NDIS.
- Close monitoring of participant satisfaction with the NDIS and the capacity to respond to satisfaction survey results.
- Building the capacity of the disability services sector to demonstrate best practice, including the development and retention of high quality workforce. This will be particularly important in areas if services are not covered by block funding and for smaller service providers. This could also include the development of support and protocols for assisting participants to engage family members or friends to undertake support activities if appropriate.
- Building community capacity to ensure that mainstream services are able to provide appropriate and accessible services to people with disability support needs. It is unclear how much of this will be provided under the NDIS Rules, but, it also will be an essential element for ensuring that the sector is able to meet the needs of people with disabilities.
- Employment of people with disabilities in the sector and the NDIA. This is a good way of ensuring that the sector and the NDIA have an appropriate culture and focus.

Recommendations

3. The RIS should reflect more in-depth consideration of the relationships between the market, government regulation, and consumer choice and how these will affect the NDIS Options described.
4. The RIS should include a consideration of innovative quality management mechanisms to monitor the satisfaction of participants and build the capacity of the participants and service providers.

The impact on choice

These issues and their attendant risks also have the capacity to influence how consumers would exercise their choice in a market for disability services and

challenge the RIS's key assumption that consumer choice will drive a market based system for the provision of disability services.

While there are many people with disabilities who are keen to exercise maximum autonomy in making choices about their own service provision, it is also the case that a significant number of consumers and carers will probably want to make quite conservative choices about their disability support, at least in the early stages of the NDIS. Reasons for this would include:

- consumers and carers who have had a poor experience with service quality may wish to choose the most highly regulated service pathway provided to ensure their safety;
- some consumers have been institutionalised by service provision and will not be inclined to make choices without the support of a familiar service provider, despite the quality of the service that they receive;
- some consumers may not want the inconvenience of change and take a path that most resembles their current service provision situation.

The positive experiences and the availability of support for decision making under the NDIS could genuinely assist consumers to gain skills and confidence to explore the benefits of a market based service system.

It is clear that whatever Options are implemented in Launch sites, they will need to cater to the wide range of consumer need described. That is, they will need to be able to offer options for maximum autonomy as well as cater to the needs of those participants who are not yet ready to change the style of their service provision but who will want to do so in the future.

Recommendation

5. The NDIS should cater to the wide range of needs of people with disabilities from those who will not necessarily want immediate change, transitioning through to those who are keen to exert full control over the brokering of their services or control of their service funding.

Impact on sustainable carer support

As highlighted by the MHCA's *Submission to the Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Bill 2012*,⁴ carer support and its sustainability needs to be given serious consideration in the delivery of NDIS services. The RIS acknowledges that:

*Carers/families are active partners in the support of participants rather than consumers of NDIS services in their own right. While there would be no requirement for a formal support needs assessment for carers, the needs of carers would be considered as part of the plan for a participant. This extends to areas such as training to improve capacity to carry out informal supports, particularly in the context of early intervention.*⁵

⁴ Mental Health Council of Australia. (2012) *Submission to the Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Bill 2012*, January 2013. Submission 552.

⁵ National Disability Insurance Scheme Joint Taskforce. Op cit, page 79.

Yet without a formal needs assessment it is unclear how the sustainability of carer supports can be identified. The process does not need to be onerous, just fair, transparent, and consistently applied.

Further, including carer needs as part of a participant's plan may not be workable where participants are not able to acknowledge the role of the carer in their support. Adequate safeguards need to be put into place to ensure that carers do not play a role in the lives of consumers where this is not the wish of the consumer. However many carers also face the situation where the supports they provide are not able to be acknowledged by the consumer that they support. The needs of these carers must be taken into account.⁶

Recommendation

6. The sustainability of carer roles should be considered in more detail and processes for the implementation of the NDIS Launch be redefined to reflect a real commitment to ensuring that carers are able to provide caring services when, and for as long as, they are needed.

Identifying risk areas in disability services

This issue may not substantially affect the regulatory impact of the NDIS, however it is still needs to be factored into decision making about the scheme's design and implementation. It demonstrates how poorly the issue of psychosocial disability related to mental illness continues to be understood by policy makers at all levels of government.

In a number of places the RIS refers to vulnerable consumers:

Participants at higher risk, for example with significant cognitive impairment and for participants who are socially isolated, would be restricted to choosing support from a list of registered providers.⁷

This essentially categorises risk areas as groups of people with particular types of disability. This definition is inconsistent with the principles underlying the United Nations Convention of the Rights of Persons with Disabilities⁸ and labelling someone with a specific mental illness does not adequately describe their support needs. At the same time it reinforces stigma and risks presuming that they have different support needs from those that they actually have. It is the support needs of individuals, not their diagnoses, which must be the subject of identification and risk analysis.

This unfortunate categorisation of high risk matters is not consistently applied across the RIS, but it needs to be rectified where it does occur.

For example, in some cases the RIS does describe support needs when describing high risk support:

⁶ MHCA describes in more detail the needs of these carers and the consequences of anosognosia in its *Submission to the Senate Community Affairs Legislation Committee Inquiry into the National Disability Insurance Scheme Bill 2012*. Op cit.

⁷ National Disability Insurance Scheme Joint Taskforce. Op cit, page 43.

⁸ United Nations. Op cit.

...support [that is] more critical to the well-being and daily living requirements of people with disability (such as tube-feeding, intubation, personal care)...⁹

This wording properly describes the support needs of individuals rather than focussing on their disability and in so doing, provides a focus for the risks that need to be managed.

Recommendation

7. The RIS should appropriately define risk associated with the provision of support needs of participants rather than allocating and managing this risk according to a person's disability type.

Conclusion

The MHCA would like to reiterate the importance of obtaining the input of mental health consumers and carers as part of the process of development of Options for the NDIS as well as the importance of considering the impact of the NDIS options on the delivery of current disability services for mental health consumers. These will be crucial for identifying the impacts and most appropriate operational success factors for the NDIS Launch.

⁹National Disability Insurance Scheme Joint Taskforce. Op cit, page 44.