



Response to the Productivity Commissions Issues Paper

National Disability Insurance Scheme (NDIS) Costs

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Preamble

VMIAC would like to thank the Productivity Commission for the opportunity to make this submission in response to the Issues Paper on National Disability Insurance Scheme (NDIS) costs.

In this report VMIAC provides a response from the consumer perspective as currently experienced in Victoria on several key matters identified within the Productivity Commission's Issues Paper. The aim of this submission is to address these key issues, providing positive recommendations for realistic and sustainable improvements to the scheme that will support the schemes costing and on-going viability.

A note on language

VMIAC recognises language is powerful. Specific terminology used to describe individuals and their experiences is of critical importance and continually evolving to better represent and reflect the diverse perspectives and reality of each individual's experience of psychosocial disability.

VMIAC welcomes ongoing discussion on this matter. For the purpose of this paper the term 'consumer' or 'participant' is used to describe people with lived experiences of mental health or emotional distress issues.

About the Victorian Mental Illness Awareness Council

THE Victorian Mental Illness Awareness Council (VMIAC) is the peak non-government organisation for people with lived experience of mental health or emotional distress issues in Victoria.

VMIAC was founded in 1981 the Year of the Disabled and provides advocacy, training, networking and capacity building on the issues of importance for its large membership base of mental health consumers across the State. VMIAC is staffed and led by people with lived experience.

VMIAC at a state level is playing an active role with regards to the introduction and implementation of NDIS supports for people with a psychosocial disability. As a peak body it has provided advocacy, advice and support to consumers, the NDIA and government departments.

Currently VMIAC is providing advocacy, education, training and support to mental health consumers across the state seeking to access and use the NDIS.

Executive Summary

In responding to the questions raised by the Productivity Commissions Issues Paper on National Disability Insurance Scheme (NDIS) costs VMIAC would like to draw attention to several critical issues of importance for mental health consumers in relation to the NDIS.

Under current transition planning for the NDIS mental health consumers across Australia are at risk of losing important psychosocial disability support services that provide inestimable benefits not only to their own lives but also to the wider social fabric of the communities in which they live.

The decision to defund a range of highly valued and well-regarded Federal and State Mental Health Programs and Services in order to pay for the costs associated with the NDIS delivering psychosocial supports to the community is ill considered and symptomatic of the chronic underfunding of mental health across Australia.

It is the belief of VMIAC that the transition to the NDIS for people with a psychosocial disability presents a unique set of problems, challenges and circumstances that requires further consideration. It is the view of VMIAC that a failure to address these issues will come at a considerable cost to the scheme, communities and vulnerable consumers currently disadvantaged by the scheme.

Within this submission VMIAC identifies a range of concerns these include:

- The failure of the NDIS to adequately cover the psychosocial disability support needs of consumers
- The gaps created by the transition arrangements of the NDIS
- The inability of the current scheme to support the full participation of people with a psychosocial disability
- The lack of 'Choice and Control' within the scheme, not only with regards to what the NDIS is providing but also in how it engages with consumers

The key recommendations contained in this submission include:

- A moratorium on the closure of PHaMs, D2DL and PIR programs until 2021
- The re-purposing of these programs to support the transition and integration of the NDIS into mainstream systems
- The commencement of an in-depth assessment and evaluation of the abilities of ILC programs and supports to meet the needs of consumers
- The adoption and use of Supported Decision Making practices and principles within the planning processes used when working with people with a psychosocial disability
- The development of a well trained and knowledgeable workforce that is well equipped to successfully engage with the diversity of people with a psychosocial disability

Issues Paper Questions

Service Gaps

Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?

VMIAC is of the view that the current NDIS transition arrangements underway in mental health will result in new service gaps within communities.

The transition of the federally funding PHaMs, D2DL and PIR programs into the NDIS and the cessation of State Community Mental Health Services will result in the loss of a range of very effective psychosocial supports.

Of concern is the transfer into the NDIS of federal funding which formerly supported the highly regarded nation-wide PHaMs, D2DL and PIR programs and at a state level; the transfer of funds formerly allocated to State Mental Health Community Support Services. The decision to transfer funding from these well-established and trusted programs into the NDIS will result in the loss of a range of very effective community focused psychosocial disability supports.

Nowhere will this be felt more keenly than in the lives of mental health consumers with moderate psychosocial support needs who fail to qualify for a NDIS package. However it is also misguided to fail to account for the loss of these services in the lives of people whose support needs at a surface level is not always as apparent.

According to Australian population modeling on mental health some 290,000 consumers currently need some form of community support; be that individual, group or non-acute residential care¹ Yet under forward estimates by the Productivity Commission the number of people with a psychosocial disability who will receive a NDIS package will be capped at 64,000.

The disparity between the number of people who will be able to access a NDIS package and the number of consumers who require some form of community support needs to be cause for alarm. When taken into account with the cessation of national and state mental health provisions a substantial proportion of consumers across the country stand to lose all or part of their much-needed psychosocial supports.

¹ <http://www.theaustralian.com.au/national-affairs/health/100000-mentally-ill-lose-ndis-cover/news-story/3f2363653fc5e86044f4ae2116395273>

In Victoria alone it has been estimated that up to 10,000 people diagnosed with a serious mental illness will be ineligible for the NDIS and are at risk of not receiving appropriate psychosocial supports²

The decision to roll PHaMs, D2DL and PIR into the NDIS is worrying in light of the vague and the yet to be proven efficacy of ILC supports that will be offered under the proviso of providing ‘Continuity of Support’

Of concern is the fact that PHaMs, D2DL PIR and Community Mental Health Services were all created as a response to address shortcomings and gaps in mainstream mental health provision. They are recovery focused, evidence based and play vital complimentary and bridging roles to mainstream services. Each of these programs has strong connections to communities whilst providing helpful and alternative supports to people who are disengaged or choose not to use mainstream services.

Currently there is no guarantee that a mental health sector shaped by the introduction of the NDIS will be able to replicate for communities the level of expertise and person centred and flexible support that is being delivered by such programs.

It is the belief of VMIAC that the impact of the social policy reforms of the NDIS needs to be monitored very closely as much will remain at stake for consumers who may find themselves significantly disadvantaged by these reforms.

We would also like to highlight that due to NDIS trial sites being piloted with in-kind funding and subsidised programs in place we have no proper understanding yet on what the NDIS can truly deliver.

Due to this ongoing uncertainty VMIAC recommends to the Productivity Commission that an in-depth assessment and evaluation of the abilities of ILC programs and supports to meet the needs of consumers needs to commence.

It is also the recommendation of VMIAC that a moratorium be placed on the closure of PHaMs, D2DL and PIR programs until 2021 by which time a proper judgment of the suitability of the NDIS to deliver comprehensive psychosocial supports to the community will be possible

VMIAC holds the view that a cautious approach to committing to retain and /or modify PHaMs, D2DL and PIR will be judicious until further adjustments to the scheme can take place.

Much needed modifications to the NDIS include:

- The streamlining of access to supports for hard to reach and difficult to engage people with complex needs

² Based on modelling undertaken for the State Government PDRSS (Psychiatric Disability Rehabilitation Support Services) reforms: Deloitte Access Economics – PDRSS Demand Modelling Report, Oct 2013.

- The development of more user friendly and culturally appropriate planning
- Greater flexibility and responsiveness within NDIS systems in order to cater for the fluctuating needs of people with a psychosocial disability
- The development within ILC's of a suite of accessible and appropriately funded psychosocial supports inclusive of Self Help Groups and Peer Run Supports
- The dismantling of structural barriers to the participation of people with a psychosocial disability within communities

From the perspective of VMIAC there is considerable cost benefits to continuing to fund PHaMs, D2DL and PIR programs whilst the scheme adapts and find its feet. These benefits include:

- The retention of a skilled, well trained and versatile workforce
- Continuity and connection for mental health consumers within a time of major reform and social change
- Viable and supportive pathways for consumers to access and exit NDIS
- Outreach capacity for the NDIS
- The provision of high quality individual and group based recovery and psychosocial supports
- Well targeted support will alleviate growing pressure and demand on the NDIS and mainstream mental health systems

Planning

Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved? How should the performance of planners be monitored and evaluated?

The current planning process for NDIS does not meet the needs of people with a psychosocial disability³ The pressure of a lengthy interview and the challenge of discussing deeply felt aspects of one's personal life, health and social functioning in an unfamiliar setting is not a fair, equitable or grounded approach to accurately gauging the on-going support needs of individuals.

VMIAC has concerns about the planning process being employed by the NDIS to determine support packages on a number of levels these include:

- The failure to provide a supportive planning process that allows for participants individual support needs to be clearly understood and addressed
- Inadequate preparation and pre-planning provided to participants seeking to enter the scheme

³ Supported Decision Making, Psychosocial Disability and the National Disability Insurance Scheme, MHA and ACT Disability, Aged and Carer Advocacy Service, Feb 2016

- Difficulties for G.P.'s and other health providers to engage in the NDIS and to provide support to consumers to obtain a suitable support package
- NDIS planners lacking appropriate experience, understanding and skills in working with people with a psychosocial disability
- The failure of the NDIS to develop a culturally sensitive planning process for CALD community members
- The worrying trend of conducting planning interviews by telephone rather than face to face which is highly impersonal, alienating and inappropriate for the task of being able to understand an individual's psychosocial support needs.
- Pressures to keep to pace with NDIS rollout targets resulting in rushed and increasing formulaic plans for consumers
- Inflexibility within the planning system to be able to respond in a timely way to changes in participant's circumstances and levels of need

VMIAC believes that these issues are contributing to variable experiences for participants engaging in the planning process of the NDIS. VMIAC has heard from consumers across the state of increasing discontent with the planning and review process.

We believe that the growing number of unfavourable experiences and outcomes for participants will over time contribute to increases in costs for the NDIS and engender mistrust and disengagement with the NDIS from consumers.

As a peak body that represents the interests of mental health consumers across Victoria VMIAC believes that it is important for the NDIS to reconsider how it can improve the usability of the scheme for consumers and address the issues we have identified.

At a deeper and more consumer focused level it is also the recommendation of VMIAC that the NDIS begins to incorporate the practices and principles of Supported Decision Making within the planning processes that determines support packages for people with a psychosocial disability.

The importance of Supported Decision Making (SDM) is recognised in the United Nations Convention on the Rights of People with a Disability (UNCRPD) that affirms that people with disabilities must enjoy the same human rights and fundamental freedoms extended to others.⁴

The UNCRPD recognises that persons with a disability may have impairments that may hinder their full and effective participation in society on an equal basis with others. It provides governments with obligations to provide access for people with a disability to supports that allow them to overcome the barriers that their disability may encounter within society⁵

It is well understood that people with a mental illness and a psychosocial disability may at times experience impaired thinking and difficulties in communication. With

⁴ https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&lang=en#EndDec

⁵ UNCRPD Article 1

regards to the NDIS planning process it is easy to understand how the pressures, stress and expectations associated with this undertaking will for many people create a range of such barriers.

In this respect the UNCRPD can act as important bridge between medical and social models of disability and supply a useful context in which to review the current practices of the NDIS planning processes in light of their suitability for use with people who have a psychosocial disability.

Within a 2016 Report commissioned by the NDIS Sector Development Fund titled ‘Supported Decision Making, Psychosocial Disability and the National Disability Insurance Scheme’⁶ a useful working definition is supplied by the United Nations Office of the High Commissioner⁷ which describes SDM as

“the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters.”⁸

When considered within the context of planning a range of Supported Decision Making tools and approaches need to be considered these include:

- The introduction of a staged planning process
- Support and encouragement for consumers to develop written statements for use in planning assessments that articulates the barriers that mental illness creates in their lives
- Clarity and agreement on the role that can be played by a participant’s supporters within planning interviews. This includes recognition of valuable contributions that can be made in this regards by Peer Workers, Advocates, family, friends, carers and others
- Greater transparency demonstrated by the NDIS with regards to the interview process with the sharing of questions that will be used in the planning interview prior to the event in order to prepare and settle participants

Task undertaken by supporters with regards to assisting participants within planning interviews could include; providing emotional support to participants, assisting participants to find the rights words, supporting the retelling of stories and experiences, holding the conversation space open when participants need to regain composure and assisting participants in getting conversations back on track.

VMIAC believes that the inclusion of Supported Decision Making principles and practices within the NDIS planning process has the potential to be restorative and will demonstrate that ‘Choice and Control for People with a Disability’ are not only desired outcomes for participants of the NDIS but are also reflected in practices and processes.

⁶ <http://www.adacas.org.au/media/1065/supported-decision-making-psychosocial-disability-and-the-ndis.pdf>

⁷ The United Nations Office of the High Commissioner for Human Rights is a part of the United Nation’s secretariat that promotes and protects human rights. See:

<http://www.ohchr.org/EN/Pages/WelcomePage.aspx>

⁸ United Nations Human Rights Council, 2009, para. 45.

Planning: Cost Pressures: Reviews: Monitoring of planners performance

To progressively implement the NDIS as required in s4 (17)(a) of the NDIS Act 2013, and further ensure financial sustainability of the NDIS as required in s4 (17)(b), we advise the NDIS acknowledge the rising uninformed cost pressure of reviews and consider effective means of managing cost overruns whilst assuring customer satisfaction and rights within the legislative framework.

VMIAC hears consumer reports of significant disconnect between the legislative principles and the actual process currently in practice.

NDIS legislation informs:

- *People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports (section 4(4));*
- *To engage as equal partners in decisions that will affect their lives, to the full extent of their capacity (s 4(8));*

The current process requires the participant to attend an interview to respond to a list of pre-determined questions by the NDIS planner. The planner takes the information away and, set against the NDIS approved process domains and price-lines, drafts a plan.

Within the NDIS process the plan is approved internally by the NDIS before being posted to the participant as their final plan. The participant is advised of a three-month window to appeal. At no point is the participant consulted for input on the draft plan pre final approval; a plan, which is to have monumental impact on their life.

The NDIS Plan arrives in the post with a covering letter advising the participant of a three-month window to appeal if unhappy with the plan, thus initiating what could be a lengthy and costly Review and Appeals process.

Consumer's report the language and format of plan development is in NDIS speak - a foreign concept to consumers. Notably, the language is also perceived as complex to many mental health practitioners.

When the printed plan appears to evidence not being heard or understood, consumers report exhaustion in pressing forward to access much needed services against disempowering barriers.

The fact that there is no person centred opportunity for consumers to work as equal partners at the planning stage negates legislative principle and is a significant driver of on-costs.

At a recent North Eastern Melbourne Area NDIS Transition conference for Stakeholders held on 20th March 2017⁹. The NDIS confirmed that an overwhelming number of people do not understand the plan and further, whilst NDIS focused on getting participants in the scheme, a significant increase in “unscheduled reviews” has put pressure on the scheme and is pushing costs up.

Issues arising indicate a concerning lack in depth of planner experience and knowledge of psychosocial disability and support planning.

It is the recommendation of VMIAC that the NDIS:

- Invest in providing consumers with a Draft Plan discussion meeting providing follow-up opportunity for consumers to read, consider and discuss the draft to signoff
- Engage experienced staff qualified to work with psychosocial disability and Person Centred Framework with a broad knowledge and or lived experience of psychosocial disability
- Develop a structure to provide training and professional supervision for staff employed to support participants planning

⁹ North Eastern Melbourne Area (NEMA) NDIS Transition Conference held on 20th March 2017 at Bell City Conference Centre, Preston