



**Psychiatric Disability Services**  
of Victoria (VICSERV)

## **Learn and Build in Barwon**

**The impact of the National Disability Insurance Scheme on the  
provision of Mental Health Services in the Barwon Launch site.**

KEY ISSUES FOR CONSUMERS, FAMILIES AND THE VICTORIAN MENTAL HEALTH SERVICE SYSTEM.

## **June 2015**

# Preface

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This paper sets out to 'tell the story' of the impact of the introduction of the National Disability Insurance Scheme (NDIS) on the provision of mental health services in the Barwon region of Victoria and to enable the Victorian Government and stakeholders to understand the implications of full scheme roll out on the Victorian mental health service system.

It deals with the experiences of consumers, carers and service providers up to February 2015.

In September 2014 the then Department of Health provided an allocation of funds to VICSERV to 'support transition of Barwon area Mental Health Community Support Services (MHCSS) consumer and services to the National Disability Insurance Scheme (NDIS) through monitoring outcomes'. It was also noted that 'collecting data and monitoring impact of transition arrangements for the launch site will likely be advantageous in the full scheme roll-out'.

This opportunity was welcomed by VICSERV and its stakeholders as it built on existing work in the launch site.

Ms Caz Healy was employed to scope a plan for the project. In this process a series of short papers were envisaged that would set out the impact of the launch on current service provision with a focus on the experience of consumers and carers. A reference group was also established to guide the completion of the papers and to consider the recommendations arising from the work.

It was agreed, early in the process, that all project reports would be completed as a matter of urgency. The desire was to capture the experience to date and to make this information available ahead of scheduled State and Commonwealth governments' meetings in the first half of 2015. This has proved difficult with limited access to shared data and the rapid rate of change as the scheme matures.<sup>1</sup>

The Barwon CEO Network has been meeting throughout the NDIS trial period, with the support of VICSERV. It has provided significant leadership of thinking in relation the possible impacts of the National Disability Insurance Scheme (NDIS) on the mental health service system in Victoria.

The grant has also allowed VICSERV to continue valuable capacity building work with providers in the Barwon area and to maintain a presence in a range of national conversations related to scheme design and policy directions.

VICSERV would like to thank Victorian Mental Illness Awareness Council (VMIAC), the peak body for mental health consumers, Tandem, the peak body for mental health carers, and Mental Illness Fellowship (Victoria) for assisting us to reflect the experiences and concerns of consumers and families involved in the Barwon National Disability Insurance Scheme (NDIS) launch site.

VICSERV also thanks Mr Paul Smith, Deputy Secretary of Department of Health and Human Services and Ms Leanne Beagley, Director Mental Health, Department of Health and Human Services for their ongoing commitment and support for this work.

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1. This Report will be supplemented by an analysis of the service provider data and in-depth case studies and vignettes.

# Contents

<b>Preface</b> .....	<b>02</b>	» The service providers' experience of implementation in the launch site.....	22
<b>Contributors</b> .....	<b>04</b>	1. Cost of participating in the trial.....	22
<b>Introduction</b> .....	<b>06</b>	2. Transitional arrangements (including block funding).....	23
<b>The Barwon Experience</b> .....	<b>08</b>	3. Clusters and pricing.....	23
» A rapidly changing environment.....	08	4. Youth residential services.....	24
» Data Snapshot.....	10	5. Quality and Safeguards.....	24
» The consumer and carer experience of implementation in the launch site.....	12	6. Housing.....	25
A new service option for people living with mental illness and their families and carers.....	12	7. Employment.....	25
1. Preparation phase.....	13	<b>National context</b> .....	<b>26</b>
2. Phasing over and Client Participation.....	14	<b>Victorian context</b> .....	<b>28</b>
3. Access and Eligibility.....	15	<b>Conclusion</b> .....	<b>30</b>
4. Planning.....	16	<b>References</b> .....	<b>32</b>
5. National Disability Insurance Agency (NDIA) Plans and supports.....	17		
6. Declining service from the National Disability Insurance Scheme (NDIS).....	18		
7. Services for Family and carers.....	18		
8. A role for advocates and navigators.....	19		
9. The link to acute mental health services.....	20		
10. Specific needs groups.....	20		
» Summary.....	21		

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VICSERV would like to acknowledge and thank the members of the Reference Group, and a number of other individuals and organisations for giving their time and insights into the experiences of the Barwon National Disability Insurance Scheme (NDIS) launch site.

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# Introduction

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## The National Disability Insurance Scheme (NDIS) was launched in Barwon on 1 July 2013.

A range of state government funded community mental health programs (Psychiatric Disability Rehabilitation Support Services (PDRSS) and Youth Residential Rehabilitation services) were included in the launch with funding contributed to the scheme by the state on an 'in-kind' basis, and with service providers continuing to receive 'block-funding' to maintain support for consumers found to be ineligible for the National Disability Insurance Scheme (NDIS) during the launch phase. In December 2013 Mutual Support and Self Help (MSSH) services in the region were also advised by the Department of Health that they would be included in the National Disability Insurance Scheme (NDIS) launch from January 2014, with the transfer of this funding to the Scheme as per the in-kind arrangement.

The Council of Australian Governments (COAG) noted in 2013 that the launch sites would provide a 'learn and build' approach so National Disability Insurance Scheme (NDIS) design could be assessed and improved:

*The [National Disability Insurance Scheme] launch sites provide governments with an opportunity to review interactions between the [National Disability Insurance Scheme] and other service systems and consider any lessons arising out of [the] launch. These applied principles, and arrangements needed to operationalise them, will be reviewed (Council of Australian Governments, 2013, p.1).*

While this approach has merit, the arrangement has nonetheless created a difficult environment for consumers and services, as well as the National Disability Insurance Agency (NDIA), with much building still to be completed at the time of the launch. This tension was acknowledged by the Agency itself in a speech by the Chairman of the Board, Dr Bruce Bonyhady:

*.... part of trialling is that you have to fly the plane, and you can't actually test a plane without ... getting it to get off the ground. Running around on the tarmac is not actually testing the plane. So look, this was a scheme that was always going to require building and learning to go on together .... (2014, p.8)*

The launch sites for the National Disability Insurance Scheme (NDIS) are critically important as they provide direct learning about the National Disability Insurance Scheme (NDIS) design as it is translated into practice, and of the potential implications of the full roll-out of the Scheme across the state. The latter is of particular relevance to the Victorian mental health system.

In Victoria, the Barwon National Disability Insurance Scheme (NDIS) launch site is testing how appropriate the design of the new National Disability Insurance Scheme (NDIS) is for people living with mental illness and psychosocial disability, and is testing the respective roles of state and federal jurisdictions. It has been the most comprehensive trial for the inclusion of mental health. In the Hunter area in New South Wales and the Western Australian launch sites, state-funded community mental health services have continued to operate with the National Disability Insurance Scheme (NDIS) services being a complement to the state funded services.

In April 2013 the Council of Australian Governments (COAG) released 'Principles to determine the responsibilities of the National Disability Insurance Scheme (NDIS) and other service systems'. This document clearly states that:

1. *The health system will be responsible for:*
  - a. *supports related to mental health that are clinical in nature, including acute, ambulatory, continuing care, rehabilitation/recovery and early intervention, including clinical support for child and adolescent developmental needs; and*
  - b. *any residential care where the primary purpose is for inpatient treatment or clinical rehabilitation, where the service model primarily employs clinical staff.*
2. *The health and community services system will be responsible for supports relating to a co-morbidity with a psychiatric condition where the co-morbidity is clearly the responsibility of that system (e.g. treatment for a drug and/or alcohol issue).*
3. *The NDIS [National Disability Insurance Scheme] will be responsible for non-clinical supports that focus on a person's functional ability, including those that enable people with mental illness or a psychiatric condition to undertake activities of daily living and participate in the community and in social and economic life.*

**(Council of Australian Governments, 2013, p. 4)**

The interface between the responsibilities of the National Disability Insurance Agency (NDIA) (and, via the Scheme, the Commonwealth Government) and those of the state governments will be crucial in determining the extent and the nature of supports provided to people with mental illness and their families.

From a stable and reasonably predictable system of community mental health provision in Barwon, the National Disability Insurance Scheme (NDIS) has been a significant change. Consumers and their families and carers are trying to understand a fundamentally different system. They have experienced changed eligibility criteria, access and assessment procedures and new models of support, and have been asked to engage in this process with a new service provider in the National Disability Insurance Agency (NDIA). State funded mental health service providers in Barwon have also faced significant change and have had the dual responsibility of assisting clients through this change and preparing their organisations for a very different operating environment.

Mental health consumers were among the last to phase across to the Scheme in Barwon, and the early stages of transition for this group, and for mental health service providers, involved a period of confusion and anxiety. Agencies, workers, consumers and carers reported inadequate education and preparation for mental health consumers and families about the National Disability Insurance Scheme (NDIS).

This paper sets out to 'tell the story' of the impact of the introduction of the National Disability Insurance Scheme (NDIS) on the provision of mental health services in the Barwon region of Victoria, relating the experiences of consumers, carers and service providers up to February 2015, and concludes by describing some of the work being undertaken to clarify the roles and responsibilities of state and federal jurisdictions.

Related work undertaken during this project includes:

- Analysis of Barwon MHCSS Service provider data – however the data was difficult to collect and no substantive conclusions could be drawn through this work.
- Case studies – which provide a comparison of service offerings available in an National Disability Insurance Scheme (NDIS) Plan with those from another Victorian MHCSS service, outside of the Barwon launch site.

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*From a stable and reasonably predictable system of community mental health provision in Barwon, the National Disability Insurance Scheme (NDIS) has been a significant change.*

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## The Barwon Experience

The introduction of the NDIS represents a significant shift in focus in the way services are provided to people living with mental illness and to their families. The impact of this change has potentially far-reaching consequences.

## A rapidly changing environment

Many mental health stakeholders (nationally and in Victoria) welcomed the inclusion of people living with mental illness in the National Disability Insurance Scheme (NDIS), believing it to be recognition of an important human rights issue and a valuable addition to the services available. However, the National Disability Insurance Scheme (NDIS) has delivered significant change from the previous stable and reasonably predictable system of community mental health provision in Barwon.

Consumers and their families and carers are struggling to understand a fundamentally different system that was designed for disability services in general rather than a system focused on disability relating to mental health conditions. They have experienced changed eligibility criteria, access and assessment procedures and new models of support, and have been asked to engage in this process with a new service provider, the National Disability Insurance Agency (NDIA), with very little or no preparation for this change.

State funded mental health service providers in Barwon have also faced significant change and have had the dual responsibility of assisting clients through this change and preparing their organisations for a very different operating environment.

The introduction of the National Disability Insurance Scheme (NDIS) represents a significant shift in focus in the way services are provided to people living with mental illness and to their families. The impact of this change has potentially far-reaching consequences. The change is not a simple transition from one model to another – the change is more accurately characterised as transformational, some have referred to the process as 'disruptive innovation'.

The Productivity Commission report on the National Disability Insurance Scheme (NDIS) (2011) noted that:

*...big changes are necessary. The current arrangements are underfunded, inefficient and unfair. They also make it hard for carers to cope since the system relies too much on their informal support. We think that a new scheme is required and that the costs of the scheme are manageable and justified.*

The Commission considers that there will be significant benefits from the new scheme – that people with disabilities and their carers will be much better off and the organisations providing supports will run more efficiently. But if the scheme is to work well over the long-run it will need to have:

- clear rules about who is entitled to what
- careful processes for assessing the needs of people with disabilities
- much more choice for people with disabilities and carers
- careful management of the costs of the scheme
- good arrangements for managing and supervising the scheme
- better jobs and conditions to encourage more people to work in disability care and support
- arrangements to help service providers operate in a new system based around the needs of the person with a disability.

Service providers, in particular, have experienced the Barwon National Disability Insurance Scheme (NDIS) trial as reflecting a belief that the service system was 'broken', and that there was an undervaluing of what has been working in Victoria and the expertise of services and workers.

From the outset there have been concerns that the design of support clusters appropriate to mental health were lagging behind other aspects of the development of the Scheme. Services in Barwon have been concerned about gaps in the supports available in the National Disability Insurance Scheme (NDIS) for people with mental illness, especially with the transfer of the Barwon Psychiatric Disability Rehabilitation Support Services (PDRSS) funding to the National Disability Insurance Scheme (NDIS).

Key challenges in the evolving Scheme have been:

- developing an understanding of impairment as a result of mental illness
- the application of this understanding to determine eligibility
- the nature of the services available.

While much of the early confusion has been resolved, many issues remain on the table. In this context Barwon has felt the full impact of the changes and of 'building the plane while flying it'.

There have been further complications created by the 'in-kind' contribution to the scheme by the Victorian Government and the subsequent arrangements around funding of agencies.

The original intent was that existing funding streams would cease on 30 June 2014, with 'in-kind' (block funding) ending and the services being 'cashed out' to the National Disability Insurance Scheme (NDIS). This was based on the expectation that all current clients in Barwon (approximately 500) would have transitioned into the Scheme by July 2014 and that services would then commence operating under the business rules and agreements of the National Disability Insurance Agency (NDIA).

However, the transfer of consumers into the Scheme trial was much more complex and slower than expected. That generated concern about the viability of providers in this context and block funding was extended to 31 December 2014.

Further extension of the block funding to 30 June 2015 was agreed in December 2014 in acknowledgement that some of these issues remained unresolved, and that the National Disability Insurance Scheme (NDIS) is not yet ready to appropriately meet the needs of people with mental illness.

The continuation of this funding arrangement has meant that providers have been able to:

- provide significant assistance to consumers to assist them to phase into the National Disability Insurance Scheme (NDIS);
- continue to provide services to meet the needs of consumers who are ineligible or not a part of the National Disability Insurance Scheme (NDIS);
- continue to provide services appropriate for the rehabilitation and support needs of consumers
- prepare systems and process by providers for the new National Disability Insurance Scheme (NDIS) environment
- continue employment of the existing experienced mental health workforce at appropriate levels and commensurate with their skills.

As a result it is not possible to categorically describe the full impact of the National Disability Insurance Scheme (NDIS) implementation.

Furthermore continuity of support for consumers ineligible for the Scheme remains a question on the table.

The following data snapshot provides some idea about progress to date.

## Data Snapshot

This snapshot is based on service provider data from October and December 2014. It was expected that the majority of consumers would have transitioned to National Disability Insurance Scheme (NDIS) by this point.

The data indicates that the number of clients assessed as eligible for National Disability Insurance Scheme (NDIS) packaged support has increased over time, and the initial experiences of confusion and frustration have lessened.

This has been attributed to:

- ongoing and persistent support by workers who continue to assist consumers through the eligibility process, which can be time and resource-intensive

- improvements in the National Disability Insurance Agency (NDIA) processes – for example the introduction of 'flexibility and bundling' of services which reduces the perceived rigidity of some plans
- increased understanding of the needs of mental health consumers – such as enabling trusted support workers to attend and assist the participant in the assessment processes
- consumers accepting that the National Disability Insurance Scheme (NDIS) is their sole option for community mental health provision, leading them to phase over to the Scheme.

However there remains a group of consumers who are not engaging with the National Disability Insurance Scheme (NDIS) and choosing not to 'phase-over' (see p17 for further discussion of this group). It remains unclear how these individuals and their families/carers will receive any support in the future when grandfathering arrangements cease.

**Table 1: Barwon agencies data snapshot (October 2014)**

Community Managed Mental Health (without MSSH <sup>**</sup> )	Total Consumers	Eligible Plans	Ineligible	Phase in – Decline <sup>*</sup>	Withdrawn
Barwon Community Managed Mental Health Service Agency Data – Oct 14	369	230	60	31	48
		62%	16%	8%	13%

**Table 2: Barwon agencies data snapshot (December 2014)**

Community Managed Mental Health (without MSSH <sup>**</sup> )	Total Consumers	Eligible Plans	Ineligible	Phase in – Decline <sup>*</sup>	Withdrawn
Barwon Community Managed Mental Health Service Agency Data – Oct 14	350	255	46	22	27
		73%	13%	6%	8%

\* 'Phase-In Declined' – those consumers who were invited by the National Disability Insurance Agency (NDIA) to test their eligibility but declined to take up this offer.

\*\* Not included above: Mutual Support Self Help (MSSH) funding consumers = 191

Some of the available figures on the transition of previous Psychiatric Disability and Rehabilitation Support Services (PDRSS) clients to the National Disability Insurance Scheme (NDIS) in Barwon show that in December 2014 approximately 73 per cent had National Disability Insurance Scheme (NDIS) plans (excluding Mutual Support and Self Help (MSSH) consumers).

Analysis of the available data indicates 20 per cent of the existing PDRSS consumers identified under Section 55 of the *National Disability Insurance Scheme Act 2013* are clearly ineligible for the National Disability Insurance Scheme (NDIS) and National Disability Insurance Scheme (NDIS) status remains unclear to the agencies for another 11 per cent of consumers. Ineligibility relates to statutory criteria regarding permanency of the condition and the assessed extent of functional impairment. However there is a large group of clients where it is unclear to the agency why the clients were deemed ineligible. The overwhelming reason for 'phase-in declined' status is 'client not responding', with administrative issues likely to account for a fair proportion of this.

The group of existing Psychiatric Disability and Rehabilitation Support Services (PDRSS) clients likely to be found ineligible are those who are younger, women, people who do not have a diagnosis of a psychotic illness, and people who are in a less stable housing situation. They are likely to be less dependent in the areas of self-care, communication and mobility than National Disability Insurance Scheme (NDIS) eligible clients but still have significant support needs with interactions and relationships, education, learning, community and economic life, domestic life and work.

There are fewer complete QDC<sup>2</sup> records among the ineligible, 'phase-in declined' and 'unknown outcome' clients, compared to National Disability Insurance Scheme (NDIS) eligible clients, indicating possibly less engagement with agencies on the part of the clients and/or perhaps a subtle change of focus within agencies towards the eligible group. Due to the missing information caution needs to be exercised in interpreting these findings. Qualitative data will provide a better understanding of the client experience and why people might choose not to engage with the NDIA in the first place or withdraw after commencing engagement.

A more thorough analysis of data was planned as part of this work however this has proved to be a very difficult process. The National Disability Insurance Agency (NDIA) releases high level data on a quarterly basis. However more detailed emerging data is treated as sensitive and is not available for ongoing consideration by external parties. This is understandable in a system that is still being built and where stakeholders and consumers may not yet have confidence in the Scheme.

Information sharing across jurisdictions will be essential as the Scheme moves closer to full roll-out. Data about eligibility and types of services offered will assist jurisdictions as they continue to clarify their obligations.

More detailed analysis of the service provider data will be provided through an additional paper developed as part of this Project.

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2. The Department of Health and Human Services (DHHS) QDC minimum data collection 2013-2014. The QDC is the reporting tool to government for Victorian Disability Services, including PDRSS. It contains client level data on PDRSS clients. (Note – the QDC does not include the Mutual Support and Self Help Program)

## The consumer and carer experience of implementation in the launch site

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The needs and expectations of consumers and their families will be central to development of the National Disability Insurance Scheme (NDIS), and their experiences in the launch sites are beginning to have a significant impact on the public debate about the role and scope of the scheme. However, the voices of people living with mental illness, and their families, have been largely absent in the implementation of the National Disability Insurance Scheme (NDIS) in Barwon, and particularly in preparing consumers for the transfer to the Scheme.

Work has commenced to describe the preferences of people living with mental illness in the Barwon region, such as that by Brophy et al. (2014). Families, carers and consumers have also led the way in designing concrete solutions to perceived areas of concern. In 2012–13 the Federal Government made grants available under the Practical Design Fund to support initiatives and resources to identify practical ways to prepare people with disability, their families and carers, the disability sector and workforce for the transition to the National Disability Insurance Scheme (NDIS). Mental Illness Fellowship Victoria conducted a project under this fund to train 'peer workers' to explain how people with a mental illness could participate in the new National Disability Insurance Scheme (NDIS) (National Disability Insurance Scheme, 2013a).

The true test has been the implementation of the scheme in each of the launch sites. The following experiences have been drawn from in-depth interviews conducted by the Victorian Mental Illness Awareness Council (VMIAC), Tandem and VICSERV with consumers and carers, and with mental health service providers (community managed and hospital networks), and through regular information sharing and capacity building meetings and targeted workshops in Barwon. They reflect the extent and depth of distress and anxiety caused by the transition process.

### A new service option for people living with mental illness and their families and carers

Many consumers have noted that when access to the National Disability Insurance Scheme (NDIS) has been achieved and a plan approved, they are generally satisfied with the supports being provided (Daya, 2015).

In particular, consumers and carers have indicated that they value the access to group programs, and that the support of their mental health worker contributed to the successful outcome.

The characteristics of the positive experiences of consumers and carers include:

- good rapport was established with the National Disability Insurance Agency (NDIA) planner
- the planner explained the process simply and provided options
- their current mental health support worker was able to provide support through the process
- the type of supports available were similar to what had been on offer previously
- service hours had increased (for some consumers)
- the ability to exercise choice of their service provider(s)
- access to services not previously available.

Notwithstanding this apparent satisfaction of consumers with the National Disability Insurance Agency (NDIA) plans, there have been a number of teething problems and concerns with the implementation of this new Scheme, as would be expected with the introduction of such a significant social development.

Consumers have experienced real distress, anxiety and difficulties in the transition to the National Disability Insurance Scheme (NDIS), but while the National Disability Insurance Agency (NDIA) has acknowledged these issues, many of them remain unresolved.

This project has sought to identify and characterise the experiences of consumers, and carers. For convenience, this report breaks the National Disability Insurance Scheme (NDIS) access and assessment process into a number of components to explore these concerns and difficulties for consumers and families.

## In their own words:

*I was accepted very quickly. (Consumer)*

*Yes. It was just a chat session. The interviewer wrote up the plan. I was a bit amazed to see the concrete 'application' of my plan to cater for my 'needs'. (Consumer)*

*With help from my key worker, I got my plan done and accepted. (Consumer)*

**Daya (2015)**

## Preparation phase

01

Mental health consumers were among the last to phase across to the Scheme and the early stages of transition for this group, and for mental health service providers, involved confusion and anxiety.

Agencies, workers, consumers and carers reported inadequate education and preparation for mental health consumers and families about the National Disability Insurance Scheme (NDIS) regarding:

- what it is
- how to gain access
- how to establish eligibility
- what types of services are available
- what should reasonably be expected in the assessment and planning process.

Carer and consumer peak bodies noted that, in particular, it would have been useful for mental health consumer- and carer-friendly information about the National Disability Insurance Scheme (NDIS) to be available through trusted sources with whom consumers and carers already have a relationship.

Concerns have also been raised about a lack of engagement with service providers, consumers and carers, early in the Scheme implementation and mental health program phasing.

*Leading, Educating, Advocating for Disability (LEAD) Barwon* was a project funded by the Victorian Government and implemented by the Committee for Geelong, commencing in October 2013 and concluding June 2014. The project worked with a group of people with a disability, informal carers and family members of people with a disability, to build their capacity to speak about their personal experience of the new National Disability Insurance Scheme (NDIS). LEAD Barwon focused on increasing individuals' confidence and ability to communicate publicly. Participants learnt new skills while sharing their needs and knowledge about how the new National Disability Insurance Scheme (NDIS) worked in their case. Over the longer term, it aimed to help ensure the Scheme is the best possible system for Victorians with a disability, their carers and families.

However, people with mental illness were deliberately excluded from LEAD Barwon, with the expectation that they would be included in later phases of the project. This exclusion added to the gap for people with mental illness in the early stages of the implementation and further raised concerns about the understanding of the needs and issues for people with mental illness and their families.

The lack of targeted mental health information and engagement was also apparent for stakeholders such as General Practitioners (GPs) and others integral to a smooth roll-out, who were unaware of their important role in the eligibility process. Consumers have, in many cases, been the educators of GPs and other workers as they have attempted to navigate the inconsistencies in the assessment process and to understand the new and evolving National Disability Insurance Scheme (NDIS).

The lack of preparation for consumers and families have led to unnecessary difficulties, which were not always dealt with appropriately at the time and possibly reflected a lack of understanding of the particular needs and issues for people with a mental illness and their families. These issues continue to impact on individuals and families and are being considered by the National Disability Insurance Agency (NDIA) under the Operational Access for Psychosocial Disability Review.

## Phasing over and Client Participation

02

### The use of Section 55 under the Act gives the National Disability Insurance Agency (NDIA) the authority to

*... require the person to give the information, or produce the document [...] to enable the functions of the NDIA [National Disability Insurance Agency]*

**(National Disability Insurance Scheme, 2013b, p. 7-8)**

Effectively this meant that service providers were required to provide their clients' details to the National Disability Insurance Agency (NDIA) so they could be contacted in relation to receiving services. This had not been expected by services and clients and was out of keeping with the previous way of doing business in Victoria:

*... [National Disability Insurance Agency] has therefore decided to utilise its powers under Section 55 of the Act .... to request the provision of this information directly from providers and sending access information to potential participants. You are aware that National Disability Services (NDS) were consulted prior to the initial cohort of letters being sent out in Barwon as the programs due to phase in over the first period did not include those experiencing mental illness. I acknowledge that letters did then go to mental health providers without any preparation from the peaks to assist these providers to understand the process.*

**(D Bowen, CEO National Disability Insurance Agency, December 2013 letter)**

Consumers reported feeling distressed that their information was given to the National Disability Insurance Scheme (NDIS) by agencies in Barwon without their consent and service providers were concerned with this apparent lack of understanding of basic principles that underpin recovery-oriented practice. These concerns continue to be expressed by consumers and service providers.

Consumer participation at all levels of organisations has been a feature of the Victorian community managed mental health services over decades. 'Nothing for us, without us' has been the mantra of the consumer movement over many years and is the foundation of consumer participation policy in Victoria and nationally. It is articulated through *Strengthening consumer participation in Victoria's public mental health service: Action plan* (Victorian Government Department of Human Services, 2009) and in *Enabling health: Taking action to improve the health of people with a disability* (VicHealth, 2014, p16).

Lack of systematic involvement of consumer advocates in the early stages of the launch resulted in 'Raise your voice Barwon' – a meeting convened by the Mental Illness Fellowship Victoria in collaboration with Tandem, Victorian Mental Illness Awareness Council (VMIAAC), Mind Works, VICSERV, SalvoConnect, Pathways and Karingal.

Daya (2015) states that this was organised because:

*'... evidence had suggested that consumers who missed out on eligibility for support under the NDIS [National Disability Insurance Scheme] may be missing out on critical support services. A number of other concerns had been raised by consumers and carers who were not necessarily in the scheme.'* (p3)

The 'Raise your Voice Barwon' report found that eligible consumers who reported the National Disability Insurance Scheme (NDIS) process as a positive experience attributed this to the support and help they received from their existing service support worker and the National Disability Insurance Agency (NDIA) planner (Daya, 2015). This underlines the importance of engagement, the need to establish a positive rapport and the value placed by consumers on the trusted long-term relationships they have developed with their workers and service providers.

## Access and Eligibility

03

In order to commence their application for eligibility, the National Disability Insurance Agency (NDIA) asks consumers to have their psychiatrist or GP complete the Access Request form. The lack of preparatory education for consumers, families and professionals such as GPs has caused a variety of problems, with many parts of the service system not clear about their roles in the National Disability Insurance Scheme (NDIS) processes.

It is unclear whether this has improved as the system has progressed.

Consumers reported that:

- Some GPs did not know about the National Disability Insurance Scheme (NDIS) nor understand their critical role in assisting the consumer to establish eligibility and complete their National Disability Insurance Scheme (NDIS) forms.
- Eligibility forms are lengthy and confusing – some consumers have been reluctant/unable to complete them.
- The cost to consumers can be significant if they require multiple visits to a psychiatrist or GP to get their letter and forms completed.
- The need for significant support and advocacy from support workers to assist consumers to complete the forms results in substantial unbillable hours for agencies and stress for consumers.

Furthermore, consumers and carers have expressed the need for all service providers and workers to have skill, knowledge and experience in trauma-informed care<sup>3</sup> as the process to date has been stressful and has not taken into account individual histories of trauma.

### In their own words:

*Filling out the application was ok apart from the doctor's attitude. (Consumer)*

*The real work of getting and staying well is done by us in conjunction with the non-government agencies; what about those of us who might get better with help. Not permanent, not eligible. (Consumer)*

*I suspect that many people who desperately require help would need a lot of guidance and advice to access support. (Carer)*

*All the applications feel complicated and challenging. I have not enjoyed this process one bit. And I'm very uncomfortable about my information given. (Consumer)*

*The doctor advised that [my] son would not get any support. Also with all the pressure of paperwork and waiting that there may be another episode. (Carer)*

*NDIA [National Disability Insurance Agency] was not satisfied with documents provided. [The] GP refused to complete the Evidence of Disability form. (Worker)*

**(Daya, 2015)**

3. (For further information see: Mental Health Coordinating Council (Mental HealthCC) 2013, Trauma-Informed Care and Practice: Towards a cultural shift in policy reform across mental health and human services in Australia, A National Strategic Direction, Position Paper and Recommendations of the National Trauma-Informed Care and Practice Advisory Working Group, Authors: Bateman, J & Henderson, C (Mental HealthCC) Kezelman, C (Adults Surviving Child Abuse, ASCA)

Language used by the National Disability Insurance Agency (NDIA) in its processes and materials, and in particular the language of permanency relating to disability that underpins the Scheme, has been identified by consumers, carers, and providers as a barrier that has impacted on access and participation for people with mental illness.

In particular consumers have expressed that the language of permanency:

- is contrary to current evidence-based recovery practice and the episodic nature of mental illness which makes it very difficult for psychiatrists and GPs to formally state that a consumer has a permanent diagnosis/disability and functional impairment
- is contrary to the recovery orientation of service delivery and support which aims to directly reduce the likelihood of a disability developing
- is known to create high levels of stigma, distress and a loss of hope for consumers to say they have a permanent disability/impairment
- creates a particular barrier to younger people (under 30 years of age) and those with moderate mental health needs, who are likely to recover but may not be eligible for support under the National Disability Insurance Scheme (NDIS).

These issues continue to distress and impact on individuals and families, and are being considered by the National Disability Insurance Agency under the Operational Access for Psychosocial Disability Review.

## Planning

04

The Planning process was frequently reported by consumers as being unfriendly, confusing and distressing.

Consumers and providers indicate that some people are uncertain of and intimidated by the new process and find it exceedingly difficult without considerable support over a long period of time (often many months) to undertake something new and unknown.

Once eligibility is determined the participant is invited in writing to meet with the National Disability Insurance Agency (NDIA) for a Planning interview. The meeting with the National Disability Insurance Agency (NDIA) Planner aims to understand their needs and aspirations and usually lasts for one hour. In some instances a second Planning

interview may be undertaken. The consumer then receives their National Disability Insurance Agency (NDIA) Plan in the mail or at a further arranged meeting.

While there is provision for an advocate of the participant's choosing to attend the planning session, consumers and providers reported that the Agency actively discouraged the participation of mental health workers in this process. It was suggested their presence was a potential conflict of interest, and could be a barrier to the exercise of choice and control by the consumer. As the National Disability Insurance Scheme (NDIS) trial has progressed this situation has improved slightly, but continues to be an issue of concern for providers and consumers and carers.

Issues of concern about this process identified by consumers included that they:

- can have difficulty in knowing and expressing their needs and goals
- may not understand the possibilities of the National Disability Insurance Scheme (NDIS) for them
- experience stress due to not knowing the Planner and being reluctant to divulge personal issues
- lack an ongoing trusting relationship in the process with 'someone who understands'

Consumers have consistently reported the value of having a support worker or advocate to assist them in the planning process, in trying to establish eligibility and in following up on plans, and that when available it contributed to the successful outcome and their positive experience of the planning process. The importance of having 'someone who understands' involved in the process is identified in a number of studies (Mind, 2015, p51). The process of a 'one off' meeting without that relationship of trust may result in poor outcomes or complete withdrawal by the consumer.

Providers report there has been some improvement in the working relationship with the Agency and a degree of collaboration in the planning process has been achieved. However, the absence or undervaluing of the role of an advocate or a trusted support worker continues to be an issue for consumers and providers.

The question of how the planning function might be provided under full implementation of the Scheme remains to be answered. In the Hunter trial site there have been suggestions that outsourcing this role to services experienced in working with people with psycho-social disability may be an option.

Consumers, carers, and providers have noted the importance of building hope at this point of transition with a strong request for recovery oriented language to be used in all forms of communication.

### In their own words:

*I filled in the forms [and] dropped them in. 4 to 5 weeks later I got a rejection letter in the mail. No contact was made with me whatsoever. They have no idea about ME. (Consumer)*

*It took five or six months from initial application to actually receive support. (Consumer)*

*Didn't understand my problems! They do now because I have an advocate. (Consumer)*

*My support worker was not listened to at the plan handover meeting (Consumer)*

*MHCSS [Mental Health Community Support Services] couldn't participate to advocate for [consumers] in planning meetings. (Consumer)*

*It's confronting to convince someone that you need help. You feel like you have two heads and no shoes. (Consumer)*

(Daya, 2015)

## National Disability Insurance Agency (NDIA) Plans and supports

05

In the main consumers reported that although they experienced difficulties and anxieties in the assessment and planning process, they are on the whole satisfied with the supports they are receiving after phasing to their National Disability Insurance Scheme (NDIS) plan.

This may be in part due to the emphasis in National Disability Insurance Scheme (NDIS) plans on disability supports such group programs and community access, which are valued by many consumers. In addition,

some consumers have changed their service provider either partly or fully as a result of the 'choice' offered under the National Disability Insurance Agency (NDIA) Plan.

Service providers have also reported that with 'block funding' still in place, many consumers are receiving more service than prior to their transition to the Scheme. In some cases the National Disability Insurance Scheme (NDIS) plan is topped up by agencies which have retained their pre-existing workforce and which may have 'legacy' services available. As previously indicated (p10) the continuation of 'block funding' is enabling the provision of similar services to those offered under Psychiatric Disability Rehabilitation Support Services (PDRSS), in effect 'masking' the full impacts of the transition to National Disability Insurance Scheme (NDIS) plans for many consumers.

### In their own words:

*We're not really defined by our illnesses, but a lot of people with stigma feel that they are defined by their illness. People need to live rounded lives, and the NDIA [National Disability Insurance Agency] packages can help them to do this. (Consumer)*

*Package has provided client with extra support & activities which he didn't have before so v. pleased (will this be ongoing post trial?) (Carer)*

*I've got a worker who takes me out for a coffee. Once a month I can go out to wherever I want to go, but I didn't get a travel component. So our hands are pretty well tied... So it sort of makes it difficult. The worker's got to come in my car, 'cause I can't go in her car. But you know, you don't understand that you need to ask for these transport things when you're filling in your form (Consumer)*

*People with mental illness need flexibility with their needs which fluctuate with the illness. I am not sure if the NDIS [National Disability Insurance Scheme] would accommodate this. (Carer)*

*Mother passed away 3/4 weeks [sic] ago. No extra support re this crisis! (Consumer)*

(Daya, 2015)

## Declining service from the National Disability Insurance Scheme (NDIS)

06

It is important to note that a group of existing consumers have declined to participate in a National Disability Insurance Scheme (NDIS) plan assessment. This group of consumers is commonly described as referred to as 'Phase-in Declined'.

The people identified in this group include consumers who:

- were unhappy with and in some cases refusing to accept the language of disability and permanency, or
- were too unwell to take part in the assessment process.

A number of these people have now been assisted by services and have received a Plan, underscoring the support and time required by some participants to complete the process.

It appears that majority of those who declined to have their eligibility assessed are attached to the Mutual Support and Self Help (MSSH) activity stream (applicable to three providers). These consumers have expressed the importance of the Mutual Support and Self Help (MSSH) service to their well-being. They stress that the service provides a safe environment, peer support, sense of belonging and connection to the world. There is a high level of concern about whether this gap will be addressed.

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## Services for family and carers

07

The Productivity Commission Report (2011) raised significant hope for families and carers of mental illness when it stated:

*The Commission believes that big changes are necessary. The current arrangements are underfunded, inefficient and unfair. They also make it hard for carers to cope since the system relies too much on their informal support. We think that a new scheme is required and that the costs of the scheme are manageable and justified.*

*The Commission considers that there will be significant benefits from the new scheme. People with disabilities and their carers will be much better off. (p7)*

Families and carers have consistently commented on the absence of services available for them in the National Disability Insurance Scheme (NDIS) and on the lack of sensitivity to their role in supporting the participant.

It is well documented that families seek out information about mental illness and look for support to develop coping strategies, problem solving skills and to overcome the sense of being overwhelmed, frustrated, and alienated from friends and family members who would normally provide support (Dixon et al, 2004). In addition, families need interventions that overcome their higher rates of depression and anxiety than the rest of the population (Stephens et al., 2011).

There has been no provision for families to independently qualify for these services within the National Disability Insurance Scheme (NDIS) scheme. Carers and families have expressed concern that the absence of these supports will reduce their capacity to provide informal support and to maintain their own health and wellbeing.

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Families are able to receive support under the National Disability Insurance Scheme (NDIS) if the person they are caring for nominates it within their package. However there have been very few instances of this occurring to date.

Consumers and families are concerned that the Scheme's focus on 'individual need' may overlook the importance of the informal care provided by families and the potential for active involvement of carers in planning and support. They are interested to understand how existing services, such as Mutual Support and Self Help (MSSH) and respite programs, will be provided into the future.

*The Information, Linkages and Capacity Building Consultation Paper* (National Disability Insurance Scheme, 2015) indicates that support for families and carers may be available under this framework. However, until there is greater clarity on how this will be provided, families and carers are at risk of missing out on the supports they need in the Barwon trial site.

### In their own words:

*Provide support for carers or you will set back disability services for years. Lots of hard work has gone into recognising the important unsung work of carers in the disability and mental health sector.* (Carer)

*Package has provided client with extra support & activities which he didn't have before so v. pleased (will this be ongoing post trial?)* (Carer)

(Daya, 2015)

## A role for advocates and navigators

08

Consumers and service providers have reported that support during the National Disability Insurance Scheme (NDIS) process was often an important factor in achieving a satisfactory plan. In many cases a number of visits to health professionals was required in order to complete the eligibility requirements and significant time and effort was expended in assisting the consumer to have their goals included in their plan.

At times, carers also require support and advocacy to access appropriate support services. This support would be valuable before the consumer's planning interview with National Disability Insurance Scheme (NDIS) and should also be available on an ongoing basis.

Consumer advocates have also noted that, while there is no provision for funding individual advocacy services in the National Disability Insurance Scheme (NDIS), the current process has relied on existing service providers and advocates to support consumers and carers through the system.

### In their own words:

*Thankfully, the advocate who came with me was just a peer. But she told them that my house was very messy and I needed it to be tidied so that friends could come over. And they included that in my package and that has just been fantastic.* (Consumer)

*With help from my key worker, [I] got my plan done and accepted.* (Consumer)

(Daya, 2015)

## The link to acute mental health services

09

Consumers and carers continue to raise concerns about the link between the National Disability Insurance Scheme (NDIS) and the broader mental health service system.

The role and importance of advocacy in this area, as well as in supporting participants to access a National Disability Insurance Scheme (NDIS) plan, has been significantly underestimated and is still to be adequately addressed.

### In their own words:

*What happens if I am on the edge or I'm in crisis? My worker no longer has time allocated to her to deal with this crisis. Their time is restricted now. There is no extra time allowed. Without my supports being in place my voices will go crazy and I will be back where I was 50 years ago. (Consumer)*

*People with mental illness need flexibility with their needs which fluctuate with the illness. I am not sure if the NDIS [National Disability Insurance Scheme] would accommodate this. (Carer)*

(Daya, 2015)

## Specific needs groups

10

Several specific needs groups have been identified from the launch site experience. Many people who have experience of mental illness are among the most disadvantaged groups in our community. Some of those most at risk include:

- Aboriginal and Torres Strait Islander People
- people with mental illness experiencing drug and alcohol problems
- culturally and linguistically diverse communities
- Gay, Lesbian, Bisexual, Transgender, Intersex and Queer (GLBTIQ) people
- women.

The Victorian Mental Illness Awareness Council (VMIAC) has raised its concerns about the particular issues facing Aboriginal and Torres Strait Islander people. Others have highlighted concerns of added complexity for migrant and refugee communities seeking to access the Scheme. Information, support and advocacy needs to be accessible and culturally appropriate for people from culturally and linguistically diverse (CALD) and Indigenous communities, including being available in different languages.

A more detailed exploration of consumer needs and experience, using in-depth case studies and vignettes, is provided as part of this Project. The work of gathering the case studies has proved quite difficult as consumers are often reluctant to repeatedly tell their stories and/or feel too unwell and vulnerable as a result of their situations.

The case studies undertaken during this project show the complexity of the support needs and raise questions about the type of services available to clients across the service continuum – from acute assessment and treatment, active rehabilitation and disability support.

## Summary

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Many of the issues and concerns raised through the implementation of the National Disability Insurance Scheme (NDIS) in Barwon are under consideration and should be addressed under the broader development of the Scheme design, prior to its further roll-out.

Critical questions emerging from the Barwon trial site include:

- What are the implications of any gaps (i.e. individual long-term recovery-focused support, family support) that emerge in models of care for consumers of services?
- Is there a fundamental difference between a National Disability Insurance Scheme (NDIS) disability-based service offering compared to a community-based recovery model of care?
- Will the NDIS support be sufficiently flexible to respond to the episodic nature of mental illness, enabling slow and sensitive engagement of consumers and the ability to step up and down the intensity of support as needed by consumers living with mental illness?
- What will happen to those consumers who are not eligible or who do not want to participate in the National Disability Insurance Scheme (NDIS), when the Mental Health Community Support Services (MHCSS) are no longer available?
- Will the pathways from clinical mental health services to Mental Health Community Support Services (MHCSS), which are critical to good outcomes, be maintained?
- Will the National Disability Insurance Scheme (NDIS) enable the families and carers of consumers to continue to receive support and education as currently provided by Mental Health Community Support Services (MHCSS)?

## The service providers' experience of implementation in the launch site

Organisations have found participating in the launch site to be a very difficult process which has used intensive time and resources.

Organisations have needed to operate on three levels:

1. Preparing and leading their organisations through major change
2. Supporting known clients to engage with a new service system
3. Participating in the 'Learn and Build' process of developing the scheme.

All services have been actively preparing their organisation for change. The National Disability Insurance Scheme (NDIS) Organisational Readiness Toolkit (National Disability Services 2014) has been very useful in assisting services to identify the key areas that services need to address and shows the range of work that organisations must undertake to participate in the Scheme.

The NDS Toolkit consists of five components (National Disability Services, 2014, p. 5)

- The Road to Readiness: a visual representation of how the new market for disability services will work, and what organisations need to do to prepare.
- The Seven Key Questions Tool: critical questions that boards and management teams need to answer in preparing their organisation for the NDIS.
- The Self-Assessment Tool: a core component of the Toolkit, [respondents are] asked to assess and rate their organisation's readiness for the NDIS.
- The Key Financial Ratios Tool: ratios that will give [respondents] an insight into [their] organisation's current financial position and how easy – or difficult – it might be for [the] organisation to transition to a more uncertain funding environment.
- Returning Your Results: a separate document in the back of the Toolkit, which [respondents] return to NDS in order to obtain [a] benchmarking report.

Barwon service providers have used this resource to focus on critical areas in the transition, including financial, people and information and knowledge management. However, participation in the launch site has required services to undertake this work in a compressed timeframe and in an uncertain environment.

All Mental Health providers in the Barwon National Disability Insurance Scheme (NDIS) trial have reported a significant impact on their balance sheet and on their workforce. In a small study conducted in Barwon on the stresses experienced by mental health workers, (Baxter, 2015) impacts included: additional stress experienced by clients, uncertainty about future practices and models of care and uncertainty about their own future employment status.

### Cost of participating in the trial

01

All organisations in the launch site report a negative impact on their balance sheet as a result of the trial.

Unfunded expenditure has been significant in three main areas:

- upgrading and improving ICT Systems, with some services investing in new purpose built software
- implementing new systems and change processes
- administering the requirements of the National Disability Insurance Agency (NDIA) plans including rostering, plan management and National Disability Insurance Agency (NDIA) portal management including major re-working associated with portal or poor functioning National Disability Insurance Agency (NDIA) IT systems.

A range of problems were experienced as the Scheme was being implemented, such as those with the operations of the 'Portal', – the electronic interface between services and the Agency, which provide access to client information and plans. The difficulties experienced in this area alone were extremely time consuming, contributing to the frustrations, costs and stress of service providers.

## Transitional arrangements (including block funding)

02

The current funding arrangements between the Victorian and Federal Governments have been the cause of much debate by providers and extension of the block funding has been sought and agreed to on two occasions. The current arrangement expires in July 2015 and service providers have suggested further extension will be required.

At February 2015 it appeared that many agencies had sought to retain their existing workforce, without renegotiating contracts or introducing new support roles. Service leaders have reported they are concerned about the potential loss of their skilled, knowledgeable and experienced workforce. Services are waiting to hear the outcome of the National Disability Insurance Scheme (NDIS) support and pricing review and how the Victorian Government will articulate its role in the provision of rehabilitation and recovery services.

At the time of this project, all parts of the specialist mental health service system were operating flexibly to support the transition of clients and to minimise gaps. This will not be sustainable in the future.

## Clusters and pricing

03

The National Disability Insurance Scheme (NDIS) supports that currently available through National Disability Insurance Scheme (NDIS) plans are a very different offering to that available across Victoria, and do not reflect contemporary and integrated mental health supports.

The National Disability Insurance Scheme (NDIS) does not purport nor aim to provide the bulk of people living with serious mental illness with comprehensive community recovery and rehabilitation service. As an insurance scheme, the National Disability Insurance Scheme (NDIS) has the potential to provide approximately 50 per cent of mental health consumers with disability services, with the Productivity Commission initially noting that the "majority" of consumers would not be eligible for a comprehensive National Disability Insurance Scheme (NDIS) package of supports (Productivity Commission, 2011).

Data is showing that a new group of consumer is being served under the National Disability Insurance Scheme (NDIS), but at this stage we are unable to identify what has happened to those who were previously getting a service under Psychiatric Disability Rehabilitation Support Services (PDRSS).

## Youth residential services

04

Youth residential rehabilitation services are currently funded by the Victorian Government and are available for young people aged 16-24 years as a stream of intensive short-term (up to one year) rehabilitation intervention to prevent disability, maintain and rebuild relationships with family and friends, support entry to study/employment and assist people to learn about their illness and its effects.

In Barwon this service is delivered as an in-kind contribution to the National Disability Insurance Scheme (NDIS) and is available through the 'shared accommodation cluster'. It is delivered through the existing facility, and block funding from the state is being drawn on for eligible participants.

Although some residents were initially deemed ineligible for the National Disability Insurance Scheme (NDIS), successful appeals meant eligibility was eventually confirmed for existing people in the program. The National Disability Insurance Scheme (NDIS) has also purchased a number of support packages for people with an intellectual disability and co-occurring mental health problems and related behavioural issues outside of the traditional age range for this program.

This emerging picture raises a number of important questions for mental health service delivery, particularly given the finite capacity of existing facilities:

- How do we maintain available resources for young people with complex mental health issues (the traditional cohort utilising these services)?
- Is it appropriate to offer a disability support approach to young people – one that assumes permanent impairment?
- How can we maintain a specialist, developmentally appropriate approach in a disability support framework?
- If the cohort utilising these services becomes more diverse, how will risks (both to safety and recovery) be managed in the residential facility?
- In full implementation, will young people who might not be considered to have permanent impairment be eligible for the scheme? If not, what services will they be able to access to provide intensive, community based intervention to prevent disability?

## Quality and Safeguards

05

Clear articulation of the Quality and Safeguard Framework for the National Disability Insurance Scheme (NDIS) and strong guidance on how this will work together with existing Victorian mechanisms are key to the successful transition for the Scheme.

To date organisations have continued to actively assess risk, maintain strong clinical linkages and refer where necessary for crisis interventions. These services have been provided in addition to the National Disability Insurance Scheme (NDIS) funded supports. Concern of a widening gap between acute support and disability support continues. Services need clarity about state and federal responsibilities.

## Housing

06

The importance of community mental health services being linked to housing has not been contemplated in the National Disability Insurance Scheme (NDIS) design. Adult and youth residential rehabilitation services are unlikely to be funded under the National Disability Insurance Scheme (NDIS), severely impacting on the wellbeing of people who would benefit from these services.

Many social housing providers enable a tenancy to progress if a tenant living with mental illness is receiving specific and ongoing support. Providers have long-established relationships with public and private housing providers and these housing and linked support arrangements contribute significantly to the housing options available for people living with mental illness. This has been a particular concern to providers, and having current National Disability Insurance Scheme (NDIS) support options cut across the tenancy support and arrangements facilitated by mental health service providers is seen as a fundamental flaw in the design.

## Employment

07

Service providers have raised concerns about the lack of supports included in National Disability Insurance Scheme (NDIS) plans associated with the access and maintenance of employment in the open or supported labour market. This is reflected in the available data.

Prior to the National Disability Insurance Scheme (NDIS), providers offered a range of vocational and job preparation supports for individuals who consistently identified employment as a key goal and aspiration. In addition providers found that many service users needed some assistance and support to access Job Services Australia and Disability Employment Services supports.

Employment support cannot be utilised by the National Disability Insurance Agency (NDIA) planners if the person is eligible for support from Job Services Australia or Disability Employment Services. As many people with psychosocial disability who are eligible for National Disability Insurance Scheme (NDIS) plans are in this situation, access to employment support systems appears to have been undermined by this aspect of the Scheme design. Providers are concerned that this adversely affects opportunities for people with psychosocial needs to secure suitable employment, which is recognised as a strong determinant of recovery maintenance.

## National context

The National Disability Insurance Scheme (NDIS) is a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers. To be eligible for the National Disability Insurance Scheme (NDIS) participants will need to demonstrate disability as the result of permanent impairment. These concepts are fundamental to the design of the National Disability Insurance Scheme (NDIS).

The inclusion of mental illness in the National Disability Insurance Scheme (NDIS) is a recognition of the human rights of people with psychiatric disability. However, it is important to note that a large proportion of the funding for mental health support and rehabilitation services is through the departments of health at Commonwealth and State levels.

At the heart of the intersections between disability and health frameworks for mental health support, and the interface between the Commonwealth and State delivery of these supports, is the clear delineation of National Disability Insurance Scheme (NDIS) and State responsibilities (Council of Australian Governments, 2013).

Currently, as the National Disability Insurance Scheme (NDIS) trial sites develop and learn from on-the-ground experiences, policy and implementation processes are moving very quickly. Several key pieces of work are now being undertaken nationally in response to the issues raised in Barwon and other launch sites, and are seeking to address many of the current concerns and teething problems.

The **Mental Health Advisory Group** is a key body in the process to ensure people with psychosocial disability are appropriately included in the full implementation of the National Disability Insurance Scheme (NDIS). The National Disability Insurance Agency (NDIA) leads this group. The purpose is to provide feedback and comment on the National Disability Insurance Agency (NDIA) mental health work plan that outlines key strategic projects on mental health that it manages. The current National Disability Insurance Agency (NDIA) work plan for mental health is a testament to its commitment to ensuring the Scheme meets the needs of people affected by mental illness and their families.

Full implementation of the National Disability Insurance Scheme (NDIS) is currently scheduled to commence in July 2016. The details of the implementation process are still unknown but are expected to be finalised through the Disability Reform Ministers Working Group by June 2015.

The National Disability Insurance Agency (NDIA) is currently prioritising a number of areas of developmental work, most of which is in response to the issues raised in Barwon and other launch sites. These developments have the potential to address a number of the significant issues identified in Barwon for people with mental illness and their families and carers. They include:

### 1. Operational Access for Psychosocial Disability Review

The aim of this work is to review access arrangements for people with a psychosocial disability to enter the National Disability Insurance Scheme (NDIS). The project will review and make recommendations for amendments to the existing processes and tools for access to the National Disability Insurance Scheme (NDIS) for people with a primary condition of psychosocial disability. It is estimated that completion will be in June 2015.

Priorities for action should include:

- co-design of language used across all National Disability Insurance Agency (NDIA) communications for mental health
- co-design of a more consumer and family friendly assessment process.

### 2. Design of Individual Supports for People with Psychosocial Disability

This work will describe in detail the range of disability supports for people who have a primary condition of psychosocial disability and make evidence based recommendations, where new support items may be needed. This project will investigate and document optimal packages of individual supports for people who have psychosocial disability associated with a mental illness. It is estimated that completion will be in June 2015.

Priorities for action should include:

- specific and evidence based mental health support types
- flexibility and bundling included in all packages
- support for Care Coordination in all packages
- support items for families and carers
- prices for support items that enable the employment of a skilled mental health workforce.

### 3. Information, Linkages and Capacity Building (ILC)

The Information, Linkages and Capacity Building (ILC) framework has now been released for feedback and consultation by the National Disability Insurance Scheme (NDIS). It is proposed that Information, Linkages and Capacity Building (ILC) supports will be available to all people with a disability, their families and carers. They will also assist community and mainstream services to be more inclusive of people with a disability, their families and carers.

The policy framework has been developed jointly between the Commonwealth and state and territory governments and it is intended that the document will be used as a guide for the National Disability Insurance Agency (NDIA) when implementing the Information, Linkages and Capacity Building (ILC) framework. It outlines the five streams of support which are available under the policy. It is estimated that completion will be June 2015.

Priorities for action should include:

- clarity regarding what services and support will be available for those not eligible for National Disability Insurance Scheme (NDIS) Individual Support Packages and the timelines for when it will be available in the launch sites.

### 4. National Disability Insurance Scheme (NDIS) Quality and Safeguarding Framework: Consultation Paper

This will be a framework for quality assurance. This is a Commonwealth Government led process that will go through two distinct phases of regulatory impact assessment. The draft paper has been released with consultation a key part of the first phase. It will proceed to the Councils of Australian Government (COAG) after the second phase. There may need to be some interim arrangements in place for the commencement of the roll-out in 2016 until the framework is finalised.

Priorities for action should include:

- clarity regarding the standards for safeguarding of quality to ensure quality service provision
- clarity regarding the responsibility between state and federal agencies for quality and risk to ensure consumers and families are protected and can raise and have concerns resolved.
- understanding of the impact of trauma, disadvantage and capacity of people affected by mental illness.

### 5. Other Developments

The outcomes of both the **National Mental Health Review** and the **Federation White Paper** will be important in the national policy environment and will impact on the future shape of services and clarify state and federal responsibilities.

## Victorian context

Victoria has a strong and comprehensive mental health system of which community managed mental health support services are an integral and important component. These services have been the benchmark for community-based recovery and rehabilitation mental health services nationally and are acknowledged for their work with individual consumers and families and carers.

Psychiatric Disability and Rehabilitation Support Services (PDRSS) have been evolving and maturing over 35 years. These services are delivered by community-managed organisations with strong involvement of consumers, carers and the local community.

Victoria has continued to strive to be a leader of service delivery in this area. The 2014 reform of Psychiatric Disability Rehabilitation Support Services (PDRSS) resulted from a desire by all stakeholders to improve the responsiveness and quality of services, as stated by the Department of Health (2013):

*The aim of these reforms is to improve health, social and economic outcome for Victorians (16-64 years) with psychiatric disability and better support carers and families in their caring role. At a system level, the reforms aim to improve service efficiency, effectiveness and quality and facilitate appropriate accountability.*

These reforms had as a key objective the preparation of services, consumers and families for the introduction of the National Disability Insurance Scheme (NDIS).

As previously indicated, the 'Principles to determine the responsibilities of National Disability Insurance Scheme (NDIS) and other service systems' outlines the interface between the Commonwealth and state responsibilities in providing mental health rehabilitation and disability support. (Council of Australian Governments, 2013, p4; See also p5 of this Report).

This interface will be crucial in determining the extent and the nature of supports provided to people with mental illness and their families under the National Disability Insurance Scheme (NDIS), and the State Government role in providing rehabilitation and recovery-oriented mental health care. Negotiations on these responsibilities are being undertaken and are expected to be resolved by June 2015 in conjunction with the agreement on the implementation plan for the roll-out of the National Disability Insurance Scheme (NDIS) across the State.

While Victoria's mental health reforms were designed to prepare services, consumers and families for the introduction of the National Disability Insurance Scheme (NDIS), many stakeholders are now recognising the need for the National Disability Insurance Scheme (NDIS) to complement the state-funded recovery-oriented rehabilitation support.

In addition to identifying its ongoing role in the provision of a contemporary mental health support system, the Victorian Government will need to address other areas in the transition to the full roll-out of the NDIS, including:

- communication on the changed offering and pathways to care
- support for consumers, families and providers in the transition process
- monitoring and addressing gaps that emerge in the implementation of the Scheme.

Many agree that the gains made during the 2014 reforms, such as a clearer focus on the needs of families and carers and a greater focus on individual rehabilitation and recovery needs, should be retained in a continuing state-funded comprehensive mental health support system.

However, a number of issues have been identified for current Mental Health Community Support Services (MHCSS) providers, and consumers and carers, as a result of the reform process. These issues should be addressed by the State Government's proposed 10 Year Mental Health Plan. Requirements include:

- **Eligibility criteria** that ensures vulnerable and disadvantaged people do not miss out on essential community based, recovery-oriented supports. This is likely to be the outcome of the application of the National Disability Insurance Scheme (NDIS) criteria in the current Mental Health Community Support Services (MHCSS), and over time this unmet need will result in increased demand for the most expensive part of the health system – emergency departments and hospitals. The State Government's commitment to restore services and monitor the impacts of the reformed system is welcomed as an initial response to this issue.
- **A workforce strategy** to ensure that Victoria retains, maintains and develops the skills required to provide quality mental health care into the future. This includes managing and responding to the demands created by the State reforms, the impending introduction of the National Disability Insurance Scheme (NDIS) and the growing demand for a peer workforce.
- **A mental health carer strategy** to provide a range of support responses including individual advocacy, respite, education, information, counselling, informal group and activity support, and peer to peer support.
- **Increasing capacity for consumer-led initiatives and peer workforce** amid strong evidence that consumer-run communities and peer initiatives are effective in supporting people to establish and maintain contributing lives.

- **Access to safe and affordable housing** as an integral component to improving health, mental health and wellbeing outcomes for people with a mental illness. There is concern that the reforms have further distanced the relationship between mental health and housing services.
- **A plan to manage the transition to and introduction of the National Disability Insurance Scheme (NDIS)**, including preparation for both consumers and service providers.
- **Reform of other PDRSS funding streams** including for Mutual Support Self Help (MSSH), Carer and Consumer Programs, Aboriginal mental health services and residential rehabilitation. Providers involved in the review of the consumer and carer programs have been highly critical of the review process and the outcomes to date. There is a need for a new process and a new approach to manage these reforms, including one which is cognisant of National Disability Insurance Scheme (NDIS) implementation from 2016.

While we know further work is required to bed down reforms, the actual impact on consumers, the workforce and services will not be known for some time. There are continuing concerns with the outcomes of the reform processes and questions as to whether the reforms have achieved what they set out to do, and more importantly whether they have created an effective and efficient community managed mental health system.

These concerns include:

- The reforms have not delivered on either diversity of providers or real and genuine choice for consumers in relation to their service provider. For example:
  - In rural areas there is often only one service provider, there are no community health services providing Mental Health Community Support Services (MHCSS) and in three of the five areas only stand-alone Mental Health Community Support Services (MHCSS) providers operate.
  - There are no specialist homelessness service providers<sup>4</sup>, or any providers targeting groups with particular needs or backgrounds.
  - There are no small providers.

- The move to a centralised intake and assessment function, in conjunction with the recommissioning process and outcomes, has resulted in a loss of local knowledge and collaboration. Providers also indicate that at this early stage of implementation, navigation may have become more difficult rather than simplified, with the centralised services being only for Mental Health Community Support Service (MHCSS) access. Consumers and carers have also indicated there are concerns with the processes now in place under this function.

#### Other Developments

The Victorian Government has indicated its commitment to the provision of contemporary recovery-oriented rehabilitation support as part of a comprehensive mental health system through its Election Platform – (*Back on the Agenda: Labor's Plan for Mental Health (2014)*). Of particular relevance will be the proposed **10 Year Mental Health Plan** and the **Mental Health Annual Report**.

We are waiting on advice about how these initiatives will be developed. In the absence of direction on these areas of work, there is significant concern about how the mainstream interface with the National Disability Insurance Scheme (NDIS) will be operationalised.

#### Key questions arising in this context:

- What are the key elements of a comprehensive state mental health system?
- Are there fundamental differences between a disability insurance scheme and a health system?
- What will be the impact of the National Disability Insurance Scheme (NDIS) on the existing service system in the medium to long term?
- How will the National Disability Insurance Scheme (NDIS) complement the current system?
- How can we safeguard the outcomes for Victorians affected by mental illness?

4. The exception is Sacred Heart Mission in consortia with Prahran Mission in the Bayside catchment.

## Conclusion

The National Disability Insurance Scheme (NDIS) is not however a rehabilitation service and cannot be an adequate replacement for rehabilitation focused services that remain the responsibility of the State Government. With changes the NDIS will be an important complementary service in a continuum of care for people living with mental illness.

The Barwon launch site has revealed that the National Disability Insurance Scheme (NDIS) has the potential to provide much-needed disability services to eligible clients.

The National Disability Insurance Agency (NDIA) reviews underway are important and have the potential to address the serious issues raised by stakeholders to date which include the language of permanent disability, assessment and eligibility processes, services, service gaps for families and the peer workforce, pricing, workforce and risk.

Barwon and Victorian mental health providers need to be involved in the work at state and Commonwealth levels to ensure the local and Victorian experience is included in future developments.

The National Disability Insurance Scheme (NDIS) is not however a rehabilitation service and cannot be an adequate replacement for rehabilitation focused services that remain the responsibility of the State Government. With changes the National Disability Insurance Scheme (NDIS) will be an important complementary service in a continuum of care for people living with mental illness.

More work will be required to prepare a response to the implementation of the National Disability Insurance Scheme (NDIS) in the Victorian context and to meet the needs of current and future people with mental illness and their families and carers. In particular, we are waiting for outcomes of the negotiation of the bilateral agreement and clarification on the state and federal responsibilities in the provision of rehabilitation support services for people with psychosocial disability.

What is needed before full roll-out commences?

### 1. Significantly improve the process of eligibility:

- The process needs to be aligned with best practice – that is, focused on functional impairment not diagnosis.
- Participants need to be informed of what supports will be available to them.

### 2. Clearly articulate the supports that will be available for people with psychosocial disability under the National Disability Insurance Scheme (NDIS):

- Service types and prices need to be defined and appropriate to the support required. This has impact on workforce planning, and organisational readiness.
- Clear articulation of **eligibility criteria, possible service types and processes** is needed for new clients
- Participants need to have information and support to understand what supports will be available to them under the NDIS;
- The National Disability Insurance Agency (NDIA) needs to know and understand what is available to people in the State system.

### 3. Implement a 'preparation phase' to improve access to the Scheme:

- Carers and consumers should have access to consumer/carer friendly information in a range of mediums (written, online, face to face), preferably from a trusted and informed source so that they can understand the Scheme and how to prepare for it.
- Clear and non-stigmatising information is required regarding the National Disability Insurance Scheme and its processes.

#### **4. Better communicate with all stakeholders in advance of the full roll-out:**

- Consumers, families, carers and services need to know clearly about how the National Disability Insurance Scheme (NDIS) will be implemented across the state and what changes in the mental health system will then result.
- All stakeholders need to know what supports will be available to people who are not eligible for the National Disability Insurance Scheme (NDIS), or who do not take up National Disability Insurance Scheme (NDIS) support packages, or for whom the National Disability Insurance Scheme (NDIS) does not meet all their mental health care needs

#### **5. Provide support for organisational readiness:**

- A minimum of 12 months preparation is required to enable organisations to prepare across all domains (ICT, Strategic, Financial, HR/Staff, clients, families, communications and administration). This will assist in preventing market failure by supporting organisations to prepare as fully as possible.
- Costs associated with transition must be acknowledged and addressed so organisations are supported to shift to a new model of care while adjusting to new service configurations.

#### **6. Fund advocacy and support for individuals and carers:**

- Consumers and families/carers should have access to a funded individual advocacy service and a support service that will assist them to prepare for their planning interview with the National Disability Insurance Scheme (NDIS). Some individuals will prefer/need a support service, some may require an advocacy service: both should be available to consumers and families/carers.
- Mental Health Care Support Services (MHCSS) clients should be able to develop a draft plan with their existing worker (who understands their needs) in preparation for their National Disability Insurance Agency (NDIA) plan.
- Information, support and advocacy should be available and accessible to members of Indigenous and culturally and linguistically diverse (CALD) communities.

#### **7. Address workforce issues:**

- A workforce strategy should be developed to provide both the mental health workforce and the primary health workers, especially GPs, to prepare for the National Disability Insurance Scheme (NDIS) in relation to mental health and their roles.
- The workforce strategy should provide particular assistance to the consumer and carer peer workforce (both paid and volunteer) to prepare for the National Disability Insurance Scheme (NDIS). This should build the capacity of this workforce to assist consumers and carers to access the scheme productively.

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