Psychiatric Disability Services
of Victoria (VICSERV)

Learn and Build: Barwon Under Full Scheme

Developments and ongoing issues in the provision of mental health services in Barwon during full-Scheme implementation of the National Disability Insurance Scheme.

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

September 2017

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Executive Summary

Learn and Build: Barwon Under Full Scheme, is a follow up report to VICSERV's *Learn and Build in Barwon (2015).*

The first report told the story of the National Disability Insurance Scheme (NDIS) during its trial in the Barwon region, which was the first site in Victoria to start delivering disability support services under the NDIS.

Two years on, *Learn & Build: Barwon Under Full Scheme* looks at how Barwon service providers have adapted since those early stages now that the NDIS has fully rolled-out in the region.

The purpose of this second report is to build on the findings of the first, and identify new and continuing issues about the Scheme's design and implementation for people with psychosocial disability, their families and carers, and the organisations who support them.

As with the first report, VICSERV has drawn on the knowledge of those experiencing the Scheme first-hand: mental health consumers, carers and service providers.

One of the biggest challenges for service providers has been adapting to a new market-based approach in the delivery of supports to people with psychosocial disability. A key feature of the NDIS is its move away from the historical block funding model and a shift to individualised funding which puts the choice and control of supports (and therefore the income a provider receives) directly in the hands of the consumer.

The case studies in this report demonstrate how mental health service providers have undergone drastic transformations and have had to adopt completely new ways of operating so that they can attempt to offer NDIS supports that are of the same high quality as those provided under previous arrangements. Often, these changes occur at the organisations' expense.

Many of the issues and questions raised in the original *Learn and Build in Barwon* report about the type and appropriateness of the supports that would be available for people with psychosocial disability, have become increasingly clear. It is now undoubtedly the case that the NDIS provides psychosocial disability supports (not psychosocial rehabilitation), and the pricing of supports reflects this.

As the community based rehabilitation component is removed from a previously-integrated psychiatric disability and rehabilitation support system, it is anticipated that the disability, clinical, health, and broader community care systems will start to feel the implications of this growing gap.

As a priority, further research and analysis is needed to identify the true implications of dismantling what was Australia's most developed and well-resourced community mental health system.

VICSERV remains a strong advocate for the NDIS and acknowledges that the NDIS will bring much needed support to many people with psychosocial disability and their families. This report recognises that there are many positive outcomes emerging for participants in the Barwon region. However, issues with the Scheme's design and processes remain, such as:

- A lack of any pre-planning support for new participants to help them understand, prepare for and access the NDIS, particularly for hard-to-reach and difficult to engage consumers.
- Inadequate provision of capacity-building supports in plans.
- Inadequate provisions for carers in plans and in the Scheme design as a whole.
- Barriers and inflexibility between the clinical and disability systems.

The lean pricing of the NDIS also has implications for the mental health workforce as organisations struggle to keep skilled and qualified mental health workers as they transform into disability support providers. This raises serious questions such as:

  – What are the risks associated for participants, workers and organisations if NDIS providers cannot afford to sustain qualified mental health workers to support people with psychosocial disability?

We acknowledge that the NDIS is in its early days and, as frequently asserted by the National Disability Insurance Agency (NDIA), is not set to reach a level of maturity for many years to come. It would also be remiss not to acknowledge that a reform as large and influential as the NDIS would not be without its problems in these early stages of the process.

However, it does appear that improvements and developments are focused on the current and future roll-out regions, seemingly leaving the Barwon region behind and, at least for the time being, in its own version of full-Scheme NDIS.

The knowledge gained to compile this report is vital in informing VICSERV's work going forward, and VICSERV continues to work across local, state and national levels to engage with mental health organisations and other stakeholders, the Victorian Government and the NDIA to influence outcomes for participants and families.

Both the Productivity Commission inquiry into NDIS costs and the Joint Standing Committee inquiry into the provision of services under the NDIS for people with psychosocial disabilities highlight some of the challenges brought about by the NDIS for people with psychosocial disability, their carers and providers. We hope that the recommendations from these inquiries bring about positive change in Scheme design, pricing and accessibility of quality supports.

As we move forward towards complete roll-out of the NDIS in Victoria in 2019, VICSERV also continues to raise the importance of psychosocial rehabilitation in an effective and contemporary mental health system; and how people with serious mental illness in Victoria will have their psychosocial rehabilitation needs met in the future.

Report recommendations

In order to address the immediate and ongoing issues that were identified from the consultations with Barwon consumers, carers and organisations, VICSERV has made the following recommendations aimed at improving access to and implementation of NDIS supports, as well as supports for those not eligible or not accessing disability services in Barwon:

1. Resources should be allocated for workers skilled in recovery-oriented practice to support potential participants in their understanding of, access to, and preparation for the NDIS. This includes active outreach for people at risk of disengaging from services and people from Indigenous and culturally and linguistically diverse communities.
2. Methods of contacting participants and NDIS language must be reviewed and modified to reflect an understanding of the needs of people with psychosocial disability and a respect for their recovery journey.
3. NDIA planners and LACs should receive appropriate training in psychosocial disability and mental health and recovery. This should include the development and delivery of a training resource aimed at improving their knowledge, skills and expertise.
4. Support Coordination should be offered as an ongoing line item for people with psychosocial disability who require capacity building to help them engage with their disability supports.
5. The NDIA should recognise the vital role that carers play in supporting a participant's wellbeing, and acknowledge their input and support needs in the planning process.
6. The Victorian Government should commit to a mental health carer strategy that recognises and supports carers of people with serious mental illness in Victoria.
7. The Victorian Government must clarify and implement a plan around how it will ensure that all people with serious mental illness in Victoria can access psychosocial rehabilitation in their community.
8. A National Mental Health Workforce strategy should be created to develop, support and maintain the mental health workforce under the current reforms. This should include the community mental health sector, the mental health peer workforce and the primary health workforce.

Introduction

Learn and Build: Barwon Under Full Scheme, is a follow up report to VICSERV's *Learn and Build in Barwon (2015)*, which described the impact of the NDIS on mental health services during the trial phase of the NDIS.

This shorter investigation examines the experiences of consumers, carers, workers, and organisations under full-Scheme NDIS in the Barwon region of Victoria; it revisits the areas of concern posed in 2015 and identifies new issues that have emerged for mental health stakeholders. The findings in this report were collected over six months of consultations with service providers, consumers, carers and other peak bodies from July to December 2016.

These investigations have revealed that although there are many positive outcomes being generated by the NDIS in Barwon, there are widening gaps in the care and services available for people with complex needs and carers, as well as significant impacts on community mental health services and their qualified workforce.

Learn and Build in Barwon (2015) described a number of key areas of concern in the Barwon region, recommending that the following issues should be addressed prior to full-Scheme roll-out:

- Significantly improve the process of eligibility;
- Clearly articulate the supports that will be available for people with psychosocial disability under the NDIS;
- Implement a 'preparation phase' to improve access to the Scheme;
- Better communicate with all stakeholders in advance of the full roll-out;
- Provide support for organisational readiness;
- Fund advocacy and support for individuals and carers;
- Address workforce issues.

This report examines whether these issues have been addressed, identifies ongoing and new areas of need, and responds to how these needs can be addressed (and by whom) in Barwon and future roll-out regions.

Significant Scheme Developments Since 2015

Inquiries and reviews

A number of inquiries and reviews have been conducted over the last 12 months which have the potential to shape the Scheme.

1. *Joint Standing Committee inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.*

In December 2016, the Joint Standing Committee on the NDIS announced it would be conducting an inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

In August 2017 the report from this inquiry was released, detailing 24 recommendations. These recommendations not only relate to Scheme design and processes (to be considered by the NDIA), but also to how state and federal governments must address the needs of people not eligible for the Scheme. The report specifically calls for clarification on how governments will provide services and address the emerging gaps created by the transition of existing services into the NDIS.

The Joint Standing Committee on the NDIS has now completed this inquiry and presented the report to Parliament.

2. *Productivity Commission Inquiry into NDIS Costs*

In February 2017, the Productivity Commission released an Issues Paper announcing a study to review the costs of the NDIS, with the Position Paper released for comment in June 2017. This study was conducted to help inform the final design of the Scheme in full, and examined factors including: the overall sustainability of Scheme costs, including current and future cost pressures; how the NDIS interacts with mainstream services; any issues with the Scheme design, including the application of market and insurance principles. The Position Paper suggested a number of key improvements relating to participants with psychosocial disability, including:

- That consideration should be given to the establishment of a specific psychosocial disability gateway within the NDIS;
- That the NDIA should employ specialist planners with mental health qualifications in order to develop plans for people living with psychosocial disability;
- That the state and federal Governments should disclose their estimates (both pre Scheme and post Scheme) of in scope and out of scope populations in a manner that is transparent and accountable;
- That the NDIA should move towards an Independent Pricing Authority, in order to ensure pricing adequately covers the service responses required, and promotes the long term sustainability of both service providers and the NDIS.

The Final Report is expected in October 2017.

3. *2017 NDIS Price Review*

Following a discussion paper released in March 2017, the 2017/2018 Price Guide was released in June 2017. This process is part of the NDIA's annual review of costs. The review aims to ensure that price controls are appropriate and continue to deliver value to participants as the Scheme grows. The 2017 / 2018 Price Guide saw a 4.5% price increase for Personal Care and Community Participation supports, with a 1.94% average increase across all other supports and a loading for supports delivered to participants in remote areas.

Information, Linkages and Capacity Building (ILC)

In November 2016, the NDIA released their Information, Linkages and Capacity-Building (ILC) Commissioning Framework.

It outlined that funding grants would be awarded to organisations to deliver services that empower people with a disability, improve access to mainstream services and build community inclusivity. It identified support for carers and for people with a disability who were ineligible for funded supports as priorities. In February 2017, the NDIA opened the first funding round of the ILC National Readiness Grants, with the second announced in August 2017.

At the time of this report, the premise of the ILC has not been achieved. Service providers comment that ILC grants are "not even on the radar" as the funding provided through the framework is so minimal and doesn't have the capacity to provide for the scope of what services were delivering under state funding, or what people ineligible for the NDIS need.

In May 2017 the NDIA announced the successful applicants of the first round of ILC grants, awarding $14million nationally across 36 organisations. Wellways Australia was the only organisation focusing on psychosocial disability to be awarded funding under 'community awareness and capacity building'.

Local Area Coordination (LAC)

Local Area Co-ordination is funded under the ILC framework to provide assistance with the planning process and connection to funded supports for people who are eligible for the Scheme, but also to connect anyone with a disability to informal and mainstream supports.

Barwon has not had a LAC function to date. However, from October 1 2017, Latrobe Community Health will begin providing LAC services in Barwon to work with a significant proportion of participants in planning, plan implementation and improving community inclusion. It is predicted the establishment of this LAC function will have several notable impacts, including LACs assuming the role of Support Connection (and some Support Coordination), which was previously included in participant's plans and implemented by providers.

Quality and safeguarding

In February 2017, the Council of Australian Governments (COAG) Disability Reform Council released the NDIS Quality and Safeguarding Framework.

The purpose of this framework is to provide nationally consistent protections for participants of the NDIS, and aims to establish the responsibilities of providers and their staff.

The framework features:

- A national complaints and serious incidents system;
- An NDIS Code of Conduct;
- A National Registrar, who will be responsible for registering providers and overseeing providers' compliance with the registration and National Standards requirements; and
- A national Senior Practitioner to enhance reporting and improve support for participants and providers.

In November 2016 the Andrews Labor Government announced that it will establish an independent, legislated registration and accreditation scheme for Victoria's disability workforce, aimed at ensuring that disability workers have appropriate skills, experience and qualifications for their role.

Both the Framework and the state-based scheme are yet to be implemented in Victoria and how effective they will be in helping to safeguard outcomes for people living with mental illness will need to be closely monitored.

The Barwon Experience – Under Full Scheme

Pre-planning

Barwon consumers, carers and providers have reported that public education around the NDIS has continued to fall short of what is needed. Services were critical of the NDIA for inadequate education for the community about accessing the Scheme and consumers acknowledged that they relied heavily on their support worker to guide their understanding of the NDIS – a time consuming process that was done in conjunction with supporting the consumer's day to day mental health needs.

One worker interviewed estimated the time spent on preparing the documentation and supporting a potential participant to access the Scheme to be approximately 20 hours of work.

Service providers commented that even now they continue to field calls, answer questions and provide direction about the NDIS from the community – none of which is funded. As the NDIS progressed in Barwon, some consumers were being turned away from service entry points and sent to their GP with no other support to understand the eligibility process. Others were 'taken in' by organisations who were finding other means or funding streams to support them.

Consumers reported that they receive better outcomes both from their NDIS plan and in their engagement with the associated supports when a support person attended their planning or plan review meeting. Many consumers who needed to apply to access the NDIS credited their worker with getting them into the Scheme, saying that without their worker organising the paperwork and giving them a stronger voice during the access and planning stages, they doubt they could have secured eligibility or a funding package on their own.

"We have people (with serious mental illness) rocking up on our door-step straight out of hospital holding a plastic bag with their medication, saying "help me". We can't turn them away because they haven't got an NDIS plan. They don't even know what the NDIS is".

– Barwon service provider

Engaging with hard to reach people outside of mainstream services

Workers made particular note of their concerns for "hard to reach" people or people who do not connect regularly with mainstream community services, such as those in the homeless community, people who choose not to access community supports or those from Indigenous or culturally and linguistically diverse backgrounds.

Workers highlighted the lack of outreach support for these client groups under the NDIS, asking *"whose responsibility is it to help these people not just access, but even start to understand the NDIS?"*

A 'hard to reach cohorts' pilot project was implemented in the Barwon region as a recommendation from the Operational Access Review for Psychosocial Disability done in 2014. However, the findings from this project are yet to be released.

A Participant's Experience

Edward has been found eligible for the NDIS. However, his mental health destabilised shortly after being accepted as a participant and he has not been able to attend a planning meeting. As a result, Edward is an NDIS participant, but he receives no support hours.*

Edward will need assistance with coping to speak to a stranger, preparation for what will happen during planning session, understanding the NDIS and what supports he requires, and support during the planning session. However, there are currently no funded services or supports to assist with this so Edward remains at home and disengaged from services and supports.

**Name has been changed*

Access and communication

Under current processes in Barwon, the NDIA attempts to engage with new people seeking access via a maximum of four phone calls and a follow-up letter.

However, Barwon workers reported that some of their clients are not comfortable speaking on telephones or answering calls from numbers they do not know. Some do not even own phones, and some have no fixed address. Workers reported that phone calls as a means to facilitate engagement can cause significant distress for some individuals and can result in people disengaging from further contact.

"The method of contacting people is just not appropriate for our consumers. Many of them won't answer a private number. There has to be a better way that shows an understanding of the needs of this group and the importance of involving the people supporting them."

– Barwon service provider

Planning meeting

Across the consumer, worker and carer groups are concerns around the 'quality' of planning meetings and resulting plans. While some participants and workers spoke very positively about their planner, the meeting and the plan they received, others were critical of this process, believing the planner did not have a good understanding of mental illness and their needs.

VICSERV noted a strong relationship between a participant's reported experience in communicating and engaging with their planner and the participant's level of satisfaction with the quality of plan that was developed. In Barwon, it seems there are a handful of planners who are addressing the needs of people with a psychosocial disability in a respectful and appropriate way.

Many participants credited their support worker for helping them to articulate their needs and goals in the planning meeting, with all participants interviewed stating they had their support worker present during the meeting. Workers highlighted the importance of a person's support worker being present during the meeting, raising the concern that many participants are not able to articulate the 'behind the scenes' work that their support worker does or the nature of the supports they were previously receiving – and that this may be overlooked in the NDIS plan.

When articulating their support needs, Barwon participants expressed how difficult they found the process of painting themselves in the "worst light" for their NDIS planning session in order to receive appropriate supports, and how this was in conflict with their desire to build self-esteem and confidence.

During the trial it was noted that the NDIA actively discouraged support workers participating in the planning process, suggesting their presence was a potential conflict of interest. Over time the NDIA has acknowledged the value of having a support worker in this planning meeting to help articulate a participant's needs. This has been welcomed by consumers and carers, who note the importance of having "someone who understands" in the room.

The value of having this support person present was echoed by the service providers who noted a significant improvement in the quality of plans when a support person attended the planning meeting.

"I wouldn't have been able to go through it (the planning process) if it wasn't for my support worker. They helped me feel less anxious and walked me through it all so I could understand"

– Barwon NDIS participant

Implementation of plans

Consultations with participants revealed a range of experiences in engaging with NDIS supports. Despite this overall variation, there was consistency amongst the group on the value of the relationship with their support worker.

One participant was "very happy" with her NDIS plan and had noticed an increase in direct support hours under the NDIS. She did note that she was able to retain the same support worker she had prior to the NDIS and that this was a contributing factor to her satisfaction.

Other participants voiced concerns, particularly around transport being under-funded and also about their connection to a support group that will not continue when it loses its current funding source. For one participant, the support group was her only connection to others with mental illness.

There was agreement amongst most of the participants that they felt anxious and uncertain about the future under the NDIS. They all said they relied heavily on their support workers to help them understand the process and valued the group opportunities to talk with each other about their experiences. However, there was concern that they "do not have enough one on one time" with their support worker (often this support worker was providing a Support Coordination function under the NDIS).

All participants interviewed for this report were able to remain with their pre-NDIS service provider and expressed their relief and satisfaction with this. Participants were aware that there were other services they could have chosen as their provider, but were happy to continue with the service and worker they had a pre-existing relationship with.

A report by the University of Melbourne titled *Choice, Control and the NDIS: Service users' perspectives on having choice and control in the new National Disability Insurance Scheme (2017)*, interviewed people with disabilities and their family members on their experience of choice and control under the NDIS in Barwon.

Although the report did not distinguish between disability 'type', findings revealed:

- Participants in regional areas (particular those with specific needs that could not be met by local providers) had limited choice as to what was available for them, with a significant portion of their funding being consumed by travel.
- Many participants relied heavily on carers, family and advocates to navigate the system.
- Many participants described challenges in accessing and understanding the huge volume of information surrounding the NDIS and commented on the administrative requirements.

Participant and Carer's Experience

Marvin lives with a psychosocial disability and has been an NDIS participant for three years. He is generally quite motivated and has always been willing to engage with workers and gets along really well with his current NDIS support worker. He was able to articulate that he wanted to do more exercise and his plan accommodates this as a result. Marvin is making progress with his life skills, which his worker is supporting.*

Marvin's parents are also benefiting. They report they have four hours respite each weekend when Marvin is out with his worker and feel comforted by the fact that Marvin has such a good relationship with his support worker.

**Name has been changed*

A Participant and Carer's Experience

Amelia has schizophrenia and struggles to keep her home tidy. She receives one hour of cleaning each week from the NDIS. However, having the cleaner in her home causes her severe anxiety. She will not let the cleaner into the house unless her mother is with her. Amelia's mother explained this to the NDIA, requesting that a mental health worker attend at the same time as the cleaner to support Amelia with her anxiety, but the plan only allows for cleaning, not for additional support to enable the cleaning to take place. As a result, although Amelia's mother no longer has to tidy the house herself, even more of her time is taken up in emotionally supporting her daughter to allow the cleaning to take place.*

**Name has been changed*

Carer experience

Barwon carers reported that they had spent a significant amount of time trying to understand the NDIS and communicate with the NDIA in the early days of the Scheme roll out. They faced barriers to speaking on behalf of their loved one when they became unwell and many felt that they were doing administrative work that should have been done by a Support Coordinator.

The Barwon carers consulted for this report said their only emotional support came from a carer consultant who ran carer support meetings and was available to contact in times of need. This group of carers all made note of the essential nature of the group in giving them an outlet to talk, cry and support each other, particularly around navigating the landscape of the NDIS. The group facilitator works for a former Psychiatric Disability Rehabilitation Support Services (PDRSS) organisation, which funds this position through income external to the NDIS. It is uncertain whether funding for this role can be maintained, placing many Barwon carers at risk of losing their only support resource.

Many carers wanted to express a desire for their son or daughter to have the skills to live independently, but did not feel comfortable or able to do this in the planning session. One carer said that her son did not have the foresight or insight to identify building his independent living skills as a goal, even though this would have greatly reduced the stress on the family situation. The nature of the planning session being focused so much on the participant meant she could not address this directly with the planner.

In their own words

"It is so disappointing that this new Scheme does not factor in my voice. It is very difficult to have an open conversation with a planner about the needs of my son and how my son's illness impacts on me in front of my son. There was no opportunity to have that heard or acknowledged"

– Barwon carer

"We are really happy with the NDIS supports our son is getting. He loves his support worker and the support worker is great at engaging with him. It's a relief to know he can go in to the community without needing us there"

– Barwon carer

Organisational and workforce impacts

Different service-delivery model

One Barwon provider described the changes to organisational structure and service delivery models to ensure viability under the NDIS as needing to be “fundamentally different” to the models of the past. Barwon service staff spoke of how they faced significant reform in how they work with clients (and each other) under an NDIS funding structure.

Individualised funding means that the organisation only receives payment for the provision of support (either face-to-face or in a co-ordination context) to a participant. As a result, providers spoke of various ways they have had to “cut back” on non-billable activities and increase the opportunities for billable activities to take place.

One provider spoke of their “mobilised workforce” – staff members spending the majority of their time “on the road” seeing clients and using mobile tablets to conduct administrative work. Another service provider made note of the fact that they have had to cut down on the time staff take to conduct administrative and ‘social’ activities in the office. Meeting billable targets, cutting back on non-billable meetings and supervision, and re-thinking training and professional development were all measures that providers mentioned they have had to implement to remain viable.

Such significant change has meant that many providers have seen a high turnover of staff and / or some resistance to the different way of working. One provider noted that it was the staff with the most experience with the previous system who had the most difficulty adjusting to the new workplace culture and expectations.

Different job roles and working arrangements

Barwon service providers noted that they have had to restructure their workforce to align with NDIS support offerings. The majority of NDIS supports fall into the ‘Core Supports’ category – an hourly income that is up to 50% less than what was previously funded for an hour of client-facing support under PDRSS. Organisations are responding to this by hiring Cert-II or Cert-III qualified disability workers, retaining the more qualified staff for the Support Coordination roles (funded at a higher rate).

Some Barwon providers are relying on other funding streams to retain their qualified mental health workforce, others have had to re-classify job roles and offer workers a lower rate of pay. Providers noted that these measures are not sustainable and losing qualified workers seems inevitable in the long-term.

The move to employing staff on short-term or casual contracts was also noted by one large provider in Barwon who said that the future was too uncertain to provide ongoing positions to new staff.

A Provider’s Experience

“Transition thinking is a mistake. Existing organisations that only know block funding will need to transform...

The organisational structures and service delivery models required for the viable delivery of NDIS supports need to be fundamentally different to the models we have traditionally used to deliver block funded services”

– Barwon provider quoted in newparadigm Summer edition (2017)

Key Areas of Concern

The comments, case studies and insights collected for this report raise a number of issues and concerns that require urgent attention in order to improve the outcomes for people with serious mental illness and their carers and families under the NDIS. These areas of need and the associated responsibilities cut across both state and federal jurisdictions.

In the longer-term the question remains of where (and how) people will have their community based psychosocial rehabilitation needs met alongside (and in addition to) clinical and disability supports.

Scheme design issues

Access, pre-planning and planning

Many participants with psychosocial disability require workers with the skills, experience and persistence to motivate and empower them to engage with supports and activities. With such a significant reform as the NDIS, it is vital that participants receive consistent and supportive help from someone they know and trust in order to understand the changes and challenges that face them. This engagement support is needed not only from the very beginning of the NDIS process, but at the application, planning and service-delivery stages to ensure people with psychosocial disability who are eligible for NDIS supports receive them, and that they are appropriate to their needs.

While some providers are supporting potential participants to understand and apply for the Scheme as unfunded activity, this is not a sustainable practice. New participants seeking eligibility and access to the Scheme are likely to be without this assistance and support in the future. This may result in more people missing out on accessing NDIS supports due to inadequate information provided during the application process.

Communication for access to the Scheme also needs to be improved both prior to and during the access process. Uptake of the scheme and the access experience could be improved by involving existing providers, family members and carers to a greater extent, and acknowledging the difficulties with the current communication practices of 'four phone calls and a letter'.

There appeared to be a direct correlation between many participants' positive reflections on the experience of their planning meeting and their perceived quality of the resulting plan. Barwon participants placed a great deal of value on their existing support worker being part of the pre-planning and planning process and many were happy that they could continue to keep their support worker under the NDIS (usually as a Support Coordinator).

Plan implementation

Some Barwon participants commented on the differences they were starting to notice between the PDRSS model and their NDIS supports. In particular, that support workers were no longer able to be as responsive to their emotional needs under the NDIS or spend as much time addressing their mental health as they had been in the past. This is a direct reflection on the NDIS offering task-focused disability supports, not psychosocial rehabilitation as was previously provided by mental health support workers.

Service providers also reported that there was a lot of variation in the quality of plans, with certain planners developing "fantastic" plans, whilst others were seemingly inappropriate and required review. Providers also noted the difference in the engagement of participants when there was a Support Coordination function in the plan compared to those who did not receive this support. One service provider described an example of a participant who had her plan for 11 months before she made contact with any service provider saying, "if she had a Support Coordinator (who could have helped her to engage), I think she would have got help a lot sooner".

Responding to complexity

The issues around engaging with the NDIS are of particular concern for vulnerable groups or people disengaged from mainstream supports, including Indigenous, culturally and linguistically diverse and homeless groups. The mechanics of the NDIS provide no incentive or support for community mental health organisations to persist with hard-to-reach clients as this work remains unfunded. With the introduction of Local Area Coordinator (LAC) partners into Barwon in October 2017, there is the opportunity for improved engagement with hard-to-reach populations. However, evident from the consultations for this report is the need for investment in active outreach programs with skilled teams of mental health workers who can work across the health, alcohol and drug, and disability sectors.

Consultations revealed that the NDIS is not a good 'fit' for participants with complex needs and who are at risk of disengaging from services, with one worker stating that, "the NDIS works for swimmers, not sinkers."

Participants who were motivated, could identify their goals and move towards them (i.e. "swimmers") were seen as benefitting from their package, maintained good relationships with their support workers and had positive feelings about the Scheme. However, participants who were withdrawn, lacking in motivation or whose mental illness meant they were unable to engage with their disability supports, did not fare well and were not achieving progress or positive outcomes despite considerable amounts of funding in their plans. This depiction is backed by a recent investigation into the NDIS by the National Institute of Labour Studies (2016), which reported that participants who were unable to effectively advocate on their own behalf, or who struggled to manage the complex NDIS processes, received a lower level of services and poorer outcomes.

Many participants with mental illness made mention of the episodic nature of their mental health needs, and how important it is to have someone to assist them to coordinate their supports, particularly when they become unwell. While NDIS plans can be flexible in terms of a participant drawing down on more funding when they require more support, participants noted that once a plan is in place, they gained more from their plan if they had a Support Coordinator involved. Participants without Support Coordination in their plan reported feeling stressed and anxious when needing to make changes to their supports.

Housing

The introduction of the NDIS has seen a transfer of funding from Adult Residential Services into the NDIS, leaving NDIS-funded shared accommodation as the only supported accommodation option for adults with high-level support needs. In Barwon, many of these housing services are run by large disability organisations.

One provider noted that most of their participants with very complex needs who cannot live independently are receiving adequate shared accommodation support in their NDIS plans. However, the participants with psychosocial disability who may not require supported accommodation, (but who still have very high support needs), are struggling. One manager commented that "the majority" of their NDIS participants with psychosocial disability experienced difficulties finding and retaining housing, with some participants submitting over ten rental applications without success. Many participants in Barwon who do receive NDIS-funded supported accommodation are living in Supported Residential Services (SRS) at their own expense.

Previously, people with mental illness on low incomes could access state-funded financial support to cover some of the costs associated with moving in to a new home. This support is not available under the NDIS and some providers are looking to short-term private grants to help their clients access independent accommodation.

The NDIS *does* offer support to assist a participant to find and maintain private housing, however this support is time-limited and requires a worker with a high level of skill and experience given the complexities of the task. One Barwon provider commented that they are using social workers or Cert-IV qualified staff to fulfill these roles – at the organisation's expense.

Some providers are allocating housing workers with the sole purpose of supporting NDIS participants to find and maintain appropriate housing. One housing worker interviewed (who has a high level of education and years of experience in mental health) described the complex nature of the role which requires relationship building with stakeholders in the housing sector, hours of meetings and paperwork and ongoing support work with the participant. This housing worker noted that a **minimum of 72 hours** of accommodation and tenancy support is required in a person's plan in order to find, apply, set up and maintain appropriate housing for a person with psychosocial disability.

This housing worker is seeing between 36 and 72 hours of this support in Barwon plans. There is currently a 6-8 week waiting list for this worker's services and the workload is increasing as participants continue to contact and access the worker for ongoing issues due to the relationship they have formed. The housing worker made note of the essential nature of the relationship they have with the participant's Support Coordinator in ensuring a successful housing placement.

Impacts beyond the NDIS

Loss of psychosocial rehabilitation

From July 1 2016, the Victorian Government began the progressive transfer of the majority of state funding for community mental health into the NDIS to fund disability supports. With the exception of Youth Residential Rehabilitation and Mutual Support and Self Help, there are no longer any state-funded community managed mental health services available in the Barwon community for people with serious mental illness.

The NDIA clearly stipulates that the Scheme is not a replacement for psychosocial rehabilitation, and that 'rehabilitation, recovery and early intervention supports' are considered the responsibility of the health system, according to the COAG Agreed Principles and Tables of Support (2015).

VICSERV supports the NDIS and the inclusion of psychosocial disability in the Scheme, and believes that the Scheme will provide positive outcomes for many Victorians with functional impairment as a result of their mental health condition. However, the NDIS is clearly not a replacement for what was a robust and highly effective psychosocial rehabilitation sector – one that is strengthened by experienced and qualified mental health workers.

The transfer of state funding to the NDIS and the resulting gap in community support raises the fundamental question:

How will people (NDIS recipients or not) with serious mental illness in Victoria have their psychosocial rehabilitation needs met in the future?

At the time of *Learn and Build in Barwon (2015)*, the Victorian Government advised that their position on their responsibilities with regard to services and supports for people with mental illness in the community would be made clear in the 10 Year Mental Health Plan (the Plan) which was being developed at the time.

Since then, the Plan has been released, with very little detail in the way of how issues around the NDIS will be resolved. The Plan simply states, *"We will work hard to ensure that the National Disability Insurance Scheme delivers what Victorians need, and we will make sure that our continuing system of community care is responsive to the particular needs of people living with mental illness and their families and carers".*

Recent Victorian Government commitments have provided some expectation that people ineligible for disability supports will get a form of community mental health care. In the 2017 / 2018 State budget, the Victorian Government announced "75,000 hours of community care" to reduce the demand on clinical mental health services, followed by a further investment of $20 million for community mental health in June 2017. The 2017 / 2018 Federal budget pledged a total of $80 million over four years (nationally) for people with mental illness who are not eligible for the NDIS – funds that will be divided and distributed only if a state or territory Government agrees to match the funding. The Victorian Government is working with the Commonwealth to determine this arrangement. At the time of writing this report, exactly what these hours and dollars will offer, who can and will access them and where, remains unknown. It is clear, however, that they will most likely come through the PHNs (state and federal funding) and clinical health system (state funding).

One individual in Barwon, who was deemed ineligible for the NDIS, talked of how she had lost access to her regular community mental health programs which are now only available to NDIS participants, commenting, *"I'm just bored. It depresses me some days. Sometimes I just call my friend and cry."* Another participant also noted his sadness at the fact that some of his peers were unable to access this support group saying, *"you see them just roaming in the streets – they're feeling less accepted, more isolated."* When asked if they would access 'mainstream' services like a neighbourhood house, the consumers interviewed were in agreement that they would feel "misunderstood" and uncomfortable at a neighbourhood house. This example would suggest that the movement of funding from community mental health services to the NDIS has generated a divide between the 'haves' and the 'have-nots'.

As more information comes to light about state and federal priorities in the mental health space, it is apparent that the disability system, clinical system, forensic and broader health system will need to evolve and work together to best support people with mental illness.

Mutual Support and Self Help

The Mutual Support and Self Help (MSSH) program was originally deemed 'in scope' for the NDIS in Barwon and included in the trial. However, this decision was reversed by the Andrews Labor Government in response to the 2014 review by Deloitte Access Economics, commissioned to evaluate the role of peer support and Mutual Support and Self Help programs. As such, MSSH provides a useful case study on the differences between the state and federal funding systems.

MSSH provides 'walk in' services that are open to anyone in the community, but most often accessed by people with mental ill health. It is centre-based and involves a focus on community engagement through group activities and trauma informed care. These programs are delivered by a qualified workforce, with staff holding at least a Certificate IV and include a strong peer component. MSSH has been described as being the "eyes and ears" for clinical services and a vital conduit between the clinical and community for people with serious mental illness, especially those who are difficult to engage.

The inclusion of MSSH in the NDIS created a number of challenges in Barwon and a MSSH staff member expressed relief that the program now sits outside of the NDIS. The NDIS eligibility requirement of 'permanent disability' meant that many individuals with serious and persistent mental illness, as well as their families and carers, (who would otherwise have made use of MSSH programs) were unable to access them. In addition, the decision to continue MSSH funding has assisted providers that run these programs to retain much of their existing qualified workforce. The flexibility of 'walk in' and centre-based programs gives a high degree of control back to individuals, as they are able to determine when and how they engage with services, and are not limited by the scope of disability supports.

MSSH provides a vital function for providing a safe and welcoming space for people who are inclined to disengage with more 'formal' services. The continuation of this program means that people who may otherwise be 'lost' in the system due to disengaging with the NDIS or clinical services can have a point of access for support. As one provider described it, MSSH "allows us to connect with those who might otherwise have difficulty engaging" – a premise that the NDIS and other state-based services continues to struggle with.

MSSH is still under consideration to be rolled-in to NDIS.

Carers' voices and needs

Learn and Build (2015) highlighted the service gap for carers of people living with psychosocial disability created by the advent of the NDIS, stating, *"There has been no provision for families to independently qualify for these services within the National Disability Insurance Scheme (NDIS). 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."* Two years later, the NDIS still does not fund or offer carer support and education, as was provided by PDRSS.

For some carers, the NDIS can offer a form of respite as support workers take on some of their previous responsibilities, but it does not fund the much needed emotional support that many had been accessing. Consultations with carers revealed that the objective of the NDIS to provide support for participants so carers can receive respite works well for carers whose loved one is actively engaged with their supports, but there is often a counteractive impact on carers who need to spend even more time encouraging and supporting their loved one to engage with their NDIS supports.

Carers continue to feel that their needs (both emotional and physical) are being overlooked in what is a highly individualised model of support provision.

Interface with clinical services

Since the end of the NDIS trial phase, Barwon service providers have started to notice an over-reliance on clinical services to support people with serious mental illness. This can be attributed to three factors:

1. The NDIS does not provide mental health supports that are deemed the responsibility of the clinical system.
2. The clinical and health system is now the only provider of direct supports for people with serious mental illness who are not eligible for the NDIS.
3. NDIS providers who were previously offering psycho-social rehabilitation are no longer providing mental-health-focused supports, placing more demand on clinical services to fill this gap.

Barwon clinical workers report that it is difficult to move clients out of bed-based services, as there are no longer community mental health workers to help in the discharge process and integrate consumers back into community. Previously, the staged process of moving clients from clinical services into community-based programs allowed for more flexibility than is currently in place under the clinical / NDIS interface.

For clients without an NDIS package, discharge is even more problematic and clinicians are faced with no community services to discharge into. Alternatively, if they want to set a client up with an NDIS package before discharge, the processing time for an NDIS application (around 28 days) far exceeds an average in-patient stay, leaving a gap in accountability and care for the that client.

Additionally, Barwon services have said there has been a noticeable change in the role of clinical workers, since the NDIS moved to full-Scheme. Clinical workers report they are working more hours, as they are having to do the work typically done by community mental health workers. They are undertaking this case-management role for clients who are ineligible for, or not currently accessing, the NDIS. Clinical workers engaging in the work previously done by community mental health workers is not only inordinately more expensive, but places even more burden on an already stretched clinical mental health system.

Impact on the workforce

The NDIS offers disability supports with the aim of building skills and capabilities around community participation and employment- and is funded accordingly. This is a very different service offering than the psychosocial rehabilitation that many people with serious mental illness in Victoria have been accessing under the state-funded system. The removal of block-funding from community mental health providers means that, for the majority of providers, they must transform into disability support services under a completely different financial model in order to survive.

The full impact of what this will mean for the workforce of the community mental health sector in Victoria is still unfolding as the sector seeks to find its place in the new system. It presents major challenges to community mental health organisations and their workers who have been trained and are committed to relationship-based consumer engagement, particular practice frameworks, work culture and values that are different to those of the new system.

The issue of the pricing of supports under the NDIS continues to be a key concern for Barwon service providers, with many organisations finding the financial model of the NDIS to be extremely challenging to sustain, particularly with regard to maintaining qualified mental health workers. Service providers were clear in their declaration that they have not ‘transitioned’ to the NDIS. Rather, they have had to ‘transform’ from community mental health organisations into disability support providers and that with this transformation comes a drastic shift in operational processes, job roles, working arrangements and the skill level of frontline staff.

A ‘deskilling’ of the workforce places a significant risk not only on the participant, but also on the worker who is required to support a person with complex mental health needs without necessarily having the skills to do so. The resulting implications for organisations and participants could be serious. One Barwon provider noted that they may have to reconsider accepting clients with complex needs given the OH&S and Work-Cover implications surrounding under-qualified workers supporting high-needs clients.

The workforce and organisational transformation that community mental health providers have experienced due to a loss of state funding has immediate and ongoing implications for Victoria's mental health workforce, including:

- The future profile of the workforce supporting people with mental illness given the number of experienced mental health workers who will not take up a role under the NDIS;
- The significant divide between lower-skilled disability support workers and highly skilled specialist workers (and no mid-level qualified mental health workers with an ongoing support role);
- The risk and OH&S issues associated with lesser-qualified disability support workers supporting people with complex mental health issues and how this will be monitored and managed;
- Ongoing training and supervision requirements for disability support workers under the NDIS;
- Capacity to adhere to the requirements of the NDIS Code of Conduct under the current pricing structure;
- The implications of the new model (including the commercial and risk considerations and a more mobile workforce) for first-tier managers and how they receive the appropriate training.

Status of Issues Identified During Trial

In *Learn and Build in Barwon (2015)*, VICSERV identified a number of issues that required response and resolution. While the progression to full-Scheme NDIS has shed more light on these issues, many of them remain.

The fact that problems identified more than three years ago remain relevant today has led to frustration and exasperation from staff of many Barwon organisations. It appears that the NDIS has 'rolled on' and continues to evolve as it moves progressively across the state and country, but has not developed fast enough to alleviate many of the concerns raised by the organisations, consumers and carers consulted for this report.

The response to and status of these issues as they are under full-Scheme have been considered and are addressed below:

1. Significantly improve the process of eligibility

The language of permanency and need to provide documentation and evidence of permanent disability is still proving challenging for consumers, carers and providers. Examples continue to surface of people who appear to meet eligibility criteria and who have provided the necessary documentation on this, being rejected upon application to the Scheme. This can cause significant distress for applicants, support workers and carers.

2. Clearly articulate the supports that will be available for people with psychosocial disability under the NDIS

Time and experience have provided more clarification on the NDIS Price Guide and the supports available for people with psychosocial disability. While people with a psychosocial disability can access any NDIS funded support if it is deemed reasonable and necessary to meet their needs, exactly what a 'quality' NDIS plan for people with severe mental illness looks like remains ambiguous. What is clear is the seemingly essential component of Support Coordination in plans for people with multiple and complex needs.

In early 2015 the NDIA and Mental Health Australia embarked on a joint project to identify optimal packages of support for NDIS participants with a psychosocial disability. *The Psychosocial Supports Design Project* (2016) (the Project) was developed in response to concerns expressed by mental health providers operating in NDIS trial sites about the applicability of NDIS supports as outlined in the NDIS Price Guide.

The broad aims of the Project were to describe the range of NDIS supports available for people who have a primary condition of psychosocial disability, and to make recommendations as to where new support items may be needed. The report made twelve recommendations for the Agency to consider, including: further investigation; changes to NDIA practices and processes; sector development; and communication activities.

Reference Packages (a benchmark funding amount for people with similar support needs and characteristics) for people with psychosocial disability is still under consideration following input from the Mental Health Sector Reference Group and a proposed project plan developed in 2015.

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

There is no funded support available in Barwon for people 'new' to the scheme to prepare for the application and planning process, leading to people being turned away from services if they do not have an NDIS plan. The need to gather and document evidence of permanent functional impact can be onerous, complex and very difficult for people with severe mental illness to manage without support. The Joint Standing Committee Report into psychosocial disability and the NDIS (2017) recommended a specialist 'psychosocial gateway' for people with psychosocial disability to gain supported access into the Scheme, but whether this will eventuate remains unknown.

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

Staff of the mental health organisations interviewed for this report felt that information, support and communication around the implementation of the Scheme (not only for them as organisations, but also for clients and families) was inadequate. Many expressed frustration around the fact that the issues, problems and concerns they raised during the trial phase were not addressed as the region moved to full-Scheme implementation.

5. Provide support for organisational readiness

In June 2016, the Victorian Minister for Mental Health, Hon Minister Foley MP announced $10 million to 16 provider and consumer peak organisations in Victoria to support people with a disability, their family and carers and service providers transition to the NDIS. VICSERV received a portion of this funding, which has enabled information provision and capacity building activities for mental health organisations ahead of NDIS transition. However, this funding is for preparation not implementation, so the activities have limited relevance for Barwon providers.

6. Fund advocacy and support for individuals and carers

The NDIS does not directly fund advocacy support through the Scheme. Individuals with a disability have access to advocacy support through the National Disability Advocacy Program (NDAP), funded through the Commonwealth Department of Social Services (DSS); intended to promote and protect all aspects of human rights enabling community participation.

Within the NDAP, new funding has been provided to set up the NDIS Appeals Program. This program was designed to ensure that people affected by reviewable decisions of the NDIA have access to a skilled disability advocate who acts as a support person, should they seek a review in the Administrative Appeals Tribunal (AAT). The Support Person assists in this process by helping individuals to understand the appeal process; assisting in putting cases to the AAT, including through help to prepare the relevant documents; and attending conferences and hearings with them where needed. There are nine NDIS Appeals Providers in Victoria; however only the Victorian Mental Illness Awareness Council (VMIAC) has specific knowledge and experience in mental health and psychosocial disability.

In circumstances where a case raises complex or novel legal issues, the NDIS Appeals Program also allows for funding for legal services, which are then provided by Legal Aid Commissions. The high profile appeal regarding the amount of transport that was funded through an NDIS plan, launched by a participant in Barwon, occurred through this process.

7. Address workforce issues

In July 2016 the Victorian Government released the *Mental Health Workforce Strategy* (2016) (the Strategy), a key deliverable of Victoria's *10-year mental health plan*. The Strategy outlines some crucial principles that are required of a future mental health workforce and a number of actions designed to:

- Improve sustainability of the mental health workforce;
- Support skill development;
- Adopt co-design principles;
- Promote the safety and well-being of workers; and
- Increase workforce collaboration and capacity to respond to mental health issues across sectors and settings;

However, workforce issues – particularly around the potential exiting of skilled mental health workers from the community mental health workforce – remains a great concern for organisations and peak bodies. At this stage the implications of the transition to the NDIS on the mental health workforce, and subsequent implications for people with psychosocial disability, are only just starting to materialise. They will require close monitoring and action as the NDIS progresses across the state.

Key Questions Going Forward

The consultations for this report have helped paint a picture of the benefits, improvements, and emerging gaps for people with psychosocial disability, their families and carers, and the implications for the mental health workforce under full-Scheme NDIS.

Serious questions remain, however, and must be given the urgent attention of state and federal governments in order identify where the gaps are under the new system of supports and how they can be addressed to prevent detrimental impact on people with serious mental illness.

VICSERV asks:

- How will the loss of a qualified mental health workforce impact on the delivery of effective and appropriate mental health supports?
- How will the risks associated with a lower qualified and less experienced workforce supporting people with psychosocial disability be managed?
- Can recovery-oriented practice be effectively incorporated into an NDIS model of care?
- How are the needs of carers being addressed?
- What are the implications and / or opportunities for mental health peer workers in the future?
- How will the NDIS adequately respond to the particular needs of Indigenous and culturally and linguistically diverse participants?
- How does the NDIS and removal of state funding impact on people with mental illness in supported housing arrangements and does the new system adequately support their needs?
- What is the Victorian Government's response to the thousands of people in Victoria with severe and persistent mental illness who are not eligible for not accessing the NDIS?
- How will people with serious mental illness get their psychosocial rehabilitation needs met?

Recommendations

In order to address the questions and concerns raised during consultations for this report, VICSERV puts forward nine key recommendations. These recommendations aim to:

- Improve the quality of NDIS supports for participants in the scheme;
- Address the gaps that are emerging for people with serious mental illness who are not accessing the NDIS;
- Consider the important needs of carers and family members;
- Address the workforce issues facing skilled mental health workers in Victoria.

VICSERV's recommendations:

1. Resources should be allocated for workers skilled in recovery-oriented practice to support potential participants in their understanding of, access to, and preparation for the NDIS. This includes active outreach for people at risk of disengaging from services and people from Indigenous and culturally and linguistically diverse communities.
2. Methods of contacting participants and NDIS language must be reformed to reflect an understanding of the needs of people with psychosocial disability and a respect for their recovery journey.
3. NDIA planners and LACs should receive appropriate training in psychosocial disability, and mental health and recovery. This should include the development and delivery of a training resource aimed at improving their knowledge, skills and expertise.
4. Support Coordination should be offered as an ongoing line item for people with psychosocial disability who require capacity building to help them engage with their disability supports.
5. The NDIA should recognise the vital role that carers play in supporting a participant's wellbeing, and acknowledge their input and support needs in the planning process.
6. The Victorian Government should commit to a mental health carer strategy that recognises and supports carers of people with serious mental illness in Victoria.
7. The Victorian Government must clarify and implement a plan around how it will ensure that all people with serious mental illness in Victoria can access psychosocial rehabilitation supports in their community.
8. A National Mental Health Workforce strategy should be created to develop, support and maintain the mental health workforce under the current reforms. This should include the community mental health sector, the mental health peer workforce and the primary health workforce.

Conclusion

Re-visiting the Barwon region since the NDIS began full-Scheme implementation revealed a picture of a region that is feeling the after-shocks from the massive disruption to service provision and support of people with serious mental illness.

The loss of state funding for psychosocial rehabilitation has meant that organisations have needed to transform into disability providers in order to survive and maintain their commitment to supporting people living with mental illness.

The eighteen months since VICSERV's initial *Learn & Build in Barwon* (2015) have seen a number of inquiries, reviews and reports on the Scheme – many of which also raise the issues and concerns identified in this report.

Largely, it seems that participants who are motivated and engaged with their NDIS supports and support worker are faring well under the NDIS, while people with more complex needs, those who require specialist supports, and people who are not accessing the Scheme, are struggling.

Evident from the consultations for this report is the need for active and effective outreach for 'hard to reach' groups. This will require investment in training workers the services where this client group connects and an approach that cuts across the clinical, disability and community sectors. Commitment to exploring improvements in NDIS implementation for people with psychosocial disability is also essential in order to improve the poor outcomes for low-functioning participants.

Maturity of the NDIS is a long term process, providing the opportunity for advocacy and policy change in Scheme design and implementation as it evolves. A spotlight needs to be kept on appropriate planning for people with psychosocial disability with a view to improving the quality of plans that best address the needs of participants. Developing an appropriate plan for someone with psychosocial disability requires an understanding of mental illness, the functional impact this can have on a consumer and the broader impact on their carer or family network.

While the NDIS is an initiative that provides much needed disability supports, it is not and never has been intended to meet the rehabilitation needs of people with serious mental illness in the community – and cannot be seen as replacement for rehabilitation-focused services. Since July 2016, state investments in community mental health appear predominantly focused on the clinical and forensic systems – and how these investments are to be spent remains unclear.

As clinical and disability services emerge as the core support offerings for people with serious mental illness in the state, it is the rehabilitation component of an effective mental health system that is the missing piece of this complex puzzle.

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