

Mind the Gap: NDIS & Psychosocial Disability

THE VICTORIAN STORY:

Insights and policy recommendations
from expert stakeholders

March 2018



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Mind Works

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SalvoConnect Barwon

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VMIAC (Victorian Mental Illness Awareness Council)

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Acknowledgements

We would like to acknowledge all expert stakeholders advocating, working in, and using NDIS and NDIS-engaged services, in the Barwon region and Victoria more broadly. This report is a synthesis of the wisdom you have gained through your direct involvement in the roll out of the psychosocial component of the NDIS and with Victorian mental health services more broadly.

We thank you for generously giving your time to share stories, experiences and insights and for engaging in a process of identifying positive, real and meaningful solutions. We trust that this report reflects your generous and thoughtful discussions and contributions.

Executive Summary

The National Disability Insurance Scheme (NDIS) presents a welcomed opportunity to increase supports and quality of life outcomes for Victorians living with psychosocial disability.

As a major initiative, it was anticipated that the Scheme would need to be modified as insights were gained, particularly regarding the needs of people living with psychosocial rather than physical, sensory or developmental disability. Trial sites across the country provided the opportunity to gain early insights to assist in ensuring that the NDIS was fit for purpose prior to national roll-out.

Barwon was the Victorian trial site. In a spirit of constructive collaboration, expert stakeholders including consumers, families, service providers and advocacy organisations from the Barwon trial site shared their on-the-ground, psychosocial disability-specific, expert knowledge. Their wisdom repeats and extends wisdom that has been articulated before, and reinforces the evidence for actions required.

Stakeholders identified two distinct areas of focus and both require urgent action.

1. Many NDIS processes and practices need immediate re-design in partnership with those who understand psychosocial disability to make them appropriate, accessible and safe for Victorians living with psychosocial disability, their families and carers.

It is important to say that NDIS support plans have been life changing for some. However, much needs to be done to enhance the accessibility, relevance and appropriateness of the Scheme for people living with psychosocial disability. Stakeholders with expertise gained through direct experience of the NDIS rollout in the Barwon region and Victoria more broadly, have articulated the issues and proposed solutions to make the promise of NDIS a reality for Victorians living with psychosocial disability. Many of the issues and corresponding policy solutions proposed are not new. They are alarmingly similar to, yet extend, those proposed by other reviews of the NDIS that have focused on the issues specific to people with psychosocial disability.⁵ The issues can be synthesised into two broad NDIS gaps that need urgent attention:

- a) the lack of NDIA assessor, planner and service provider expertise in psychosocial disability is causing poor and inequitable service at best and severe trauma and harm at worst, and
- b) inadequate funding models are resulting in a lack of sustainable, and safe service or support options for those fortunate enough to be assessed as eligible for the Scheme.

It is acknowledged that the NDIA has started to engage expert stakeholders on some of the more pressing concerns, including the design of a specialised pathway to improve the pre-planning, planning, implementation and review process for people with psychosocial disability along with specialised pathways for Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD), and complex clients. In addition, the NDIA has publicly committed to ceasing the distressing practice of phone interviews. However this stakeholder engagement is limited and very late in the NDIS roll-out schedule. More resources need to be directed to fix obvious and serious problems sooner and prevent negative impacts on participants, carers and families in roll-out regions.

2. Victoria and the Commonwealth have chosen a short-sighted, quick-fix method of finding money to fund the NDIS for people with psychosocial disabilities.

While only around 10% of Victorians living with severe mental illness are expected to be eligible for the NDIS, critical community mental health services supporting all Victorians living with severe mental illness are being decommissioned to fund the Scheme.

For many years there has been unmet demand for services in the community in Victoria due to underinvestment in the mental health system. Victoria has the lowest per capita funding for mental health services, covering fewer people for their mental illness needs, with greatly reduced community mental health care and fewer beds than the national average.¹ Victoria's once benchmark mental health system lags behind the other states and territories.

The redirection of funding from the existing Victorian Government Mental Health Community Support Services (MHCSS) program and Commonwealth programs to fund the NDIS is highlighting existing mental health service gaps and creating new gaps and uncertainty. Of great concern is the loss of psychosocial rehabilitation, a central

pillar of community mental health, which is the step down from clinical or acute care. Consequently, many thousands of Victorians living with mental illness will not have their needs met. With limited community mental health services available to prevent people becoming unwell, provide early intervention, and support them to move into the community from acute settings, the burden will increasingly fall to hospital emergency departments, ambulance services, the police and the justice system. Mental health presentations in emergency departments alone have jumped by 19% in three years to more than 52,000 per year – this equates to one admission every 10 minutes.²

Consequently, Victorians living with mental illness are facing the potentially negative outcomes predicted and warned against in the 2014 National Mental Health Commission report.³ They are facing a mental health service system that is rapidly shifting in the opposite direction to all current national and international mental health policies and trends.^{4,5} The National Mental Health Commission recommendations, agreed to by the Australian Government,⁶ called for a shift in mental health funding allocation from acute and clinical services towards greater psychosocial, community-based services and supports. Independent costings demonstrated the longer-term financial and mental health wisdom of this. As a consequence of the method chosen to fund the NDIS, the reverse has occurred. Thus, as the NDIS rolls out, many Victorians living with severe mental illness are likely to be increasingly worse off in terms of their access to support and services.

Victoria and the Commonwealth have chosen a short-sighted, quick-fix method of finding money to fund the NDIS for people with psychosocial disabilities.

The range of supports and services for Victorians living with severe mental illness that are disappearing include services and supports to:

- manage their illness
- build their capacity to live productive and meaningful lives
- strengthen their mental health
- meet, connect with, and learn from others with lived experience of mental illness
- access and maintain housing
- navigate and access the diverse range of services they need.

These are also the services that support people to avoid deterioration in their mental health and to avoid or reduce frequency and duration of relapse and acute, expensive, episodes of illness. These de-funded programs are also the services that reduced the risk of people developing a long-term disability. This method of funding the NDIS may well lead to a greater proportion of Victorians ultimately reaching the level of disability needed to qualify for the Scheme. The solution is immediate and ongoing investment by the Victorian Government in community mental health services.

Programs and supports for family members and others caring for people with mental illness are also being dismantled to fund the NDIS. Those caring for the approximately 90% of Victorians living with severe mental illness who are not in the Scheme are increasingly losing the services and supports that helped them to best care for their loved one and to maintain their own mental health and wellbeing. Again, the inevitable and globally evidenced consequence of this is carer burnout and thus ultimately greater costs on the mental health system.

Wisdom from expert Victorian stakeholders, including service users, families, service providers and advocacy organisations are summarised briefly below and detailed within the report. It repeats and extends wisdom that has been articulated before. NDIA action is urgent and overdue. Equally, the Victorian and Commonwealth Governments need to take urgent, coordinated action to reverse the growing catastrophe facing over 90% of Victorians living with severe mental illness and the families and carers who support them.

[1] McGorry P (2017). Mental Illness: The health crisis we are happy to turn a blind eye to. The Sydney Morning Herald. Available from: <http://www.smh.com.au/comment/mental-illness-the-health-crisis-were-happy-to-turn-a-blind-eye-to-20171128-gzuj72.html>

[2] Victorian Department of Health and Human Services, Mental Health Annual Reports. In 2013-14, there were 43,993 mental health related presentations in emergency departments. In 2016-17, there were 52,427 presentations

[3] National Mental Health Commission. Contributing lives, thriving communities: Report of the national review of mental health programmes and services. Sydney: NHMC, 2014.

[4] Council of Australian Governments. The Fifth National Mental Health and Suicide Prevention Plan. COAG, 2017. Available from: <http://www.coaghealthcouncil.gov.au/Publications/Reports>

[5] Victorian Government (2015). Victoria's 10-year mental health plan. Victorian Government. Available from: <https://www2.health.vic.gov.au/mental-health/priorities-and-transformation/mental-health-priorities-for-victoria>

[6] Australian Government (2015). Australian Government response to Contributing Lives, Thriving Communities – Review of Mental Health Programmes and Services. Available from: <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-review-response>

SUMMARY: STAKEHOLDER IDENTIFIED GAPS AND PROPOSED SOLUTIONS

I. Experiences of, and support pathways for, Victorians living with mental illness who are NOT engaged with or eligible for NDIS support

THE GAPS AND ISSUES (explained in further depth within the report):

- Dramatic loss of services for the vast majority (estimated to be as many as 90%) of Victorians living with severe episodic and persistent mental illness.
 - Services with a low threshold or minimal requirements for engagement.
 - Community-based services supporting recovery and psychosocial rehabilitation.
 - Peer support and peer-connection.
- Increasing use of acute and clinical services.
- Reduced sustainability of informal supports from family and carers.

PROPOSED POLICY SOLUTIONS (explained in further depth within the report):

1. Release KPMG report on Victorian mental health services (completed February 2017, but not released) and use that, with recommendations below, to develop a vision and plan to ensure a comprehensive, contemporary, recovery, and community-focused mental health system in Victoria.
2. Immediate investment in a short-term 'safety net' of psychosocial rehabilitation and long-term investment in community-based services.
3. Immediate investment in the skilled and experienced community-based mental health workforce to ensure that the capacity to deliver the above safety net is maintained as well as ensuring this workforce is available to implement future visionary mental health plans in Victoria.
4. Victorian Government immediately matches the Commonwealth's psychosocial funding offer.
5. Ongoing, systematic and transparent data collection to inform future developments.

II. Experiences of Victorians living with psychosocial disability who ARE engaging with NDIS

THE GAPS AND ISSUES (explained in further depth within the report):

- NDIS has been very positive for some.
- Many people are not applying (choosing not to test their eligibility) or are withdrawing mid-way through the application process due to:
 - lack of knowledge or understanding of the Scheme
 - overwhelming complexity of the process
 - prohibitive costs of acquiring specialist reports
 - lack of advocacy and support
 - lack of culturally appropriate support – particularly for Aboriginal and Torres Strait Islander people
 - lack of understanding that other support pathways would soon cease to exist
 - paranoia and anxiety about the Scheme
 - fluctuating capacity to engage in the process
 - rejecting the label or language of 'permanence'.
- Many people are assessed as ineligible by NDIA due to:
 - inability to collect the extensive level of evidence required
 - extreme complexity of the application process
 - limited understanding of NDIS requirements by GPs and other evidence providers
 - unfair and inequitable assessment process stemming from assessors lack of understanding of psychosocial disability
 - the fluctuating nature of psychosocial disability
 - denial of face-to-face assessment
 - lack of adequate support and advocacy at time of assessment

- anosognosia (inability to recognise a disorder that is clinically evident) and embarrassment.
- Extensive time delays.
- Planning meetings do not align with and respect the needs of many living with psychosocial disability.
- Ill-fitting plans for many who are eligible.
- Lack of service providers to 'action' a plan.
- Significant reductions in revised plans.
- Rigidity or inflexibility if and when plans need to be amended or reviewed.

PROPOSED POLICY SOLUTIONS (explained in further depth within the report):

1. Implement a specialist psychosocial gateway to the NDIS.
2. Incorporate Local Area Coordination (LAC) and Planner roles into the specialist psychosocial gateway.
3. Establish a funding pool available for specialist assessments required by NDIA.
4. Fund assertive outreach for hard to reach and hard to engage populations.
5. Design and deliver NDIS processes at the community level to enhance NDIS accessibility and cultural relevance.
6. Review and reduce the overwhelming level of evidence required from applicants.
7. Include timeframes for actions within LAC and Planner key performance indicators.
8. Immediately cease over-the-phone assessments and planning meetings.
9. Ensure advocates and supports are invited and included as part of standard, required practice.
10. Establish an evidence base to enhance NDIA capacity to understand the difference between those who need maintenance support and those who would benefit from supports to improve functioning.
11. Establish a better assessment tool.

III. Carers and family member experiences

THE GAPS AND ISSUES (explained in further depth within the report):

Prevented or not able to support their loved one through the NDIS process

- Family and carers have typically not been informed about or included in their loved one's assessment and planning processes.
- NDIS does not have a broad understanding of who might be a participant's family, carer or other significant support persons.
- Families and carers are overwhelmed by the complexity of the application process.

Carers and family members are not having their own needs met

- Carer support services are only included in an NDIS package if the participant requests funding for such services.
- Most families and carers are unaware that they can be supported through the plan.
- Supports and services available to families and carers through the NDIS are severely limited.
- Funding previously available to support carers to sustain their own wellbeing is ceasing as it is transferred to the NDIS.

PROPOSED POLICY SOLUTIONS (explained in further depth within the report):

1. Train Planners in culturally-aware, family inclusive practice.
2. Require active encouragement of family and carer inclusion at consultations.
3. Enhance carer and community education programs.
4. Immediately implement a fully funded carer strategy separate from the NDIS.

IV. Community mental health services and organisations**THE GAPS AND ISSUES** (explained in further depth below):**Engaging with, and providing services and supports within the NDIS:**

- Collapsing, merging and electing not to provide services under the NDIS.
- Running at a loss.
- Bending the rules to survive.
- Losing a talented mental health workforce.
- Staff training, support and supervision reduced to risky levels.
- Lamenting the loss of a person-centred model for this new business driven model.

PROPOSED POLICY SOLUTIONS (explained in further depth below):

1. Establish an independent pricing body, separate to the NDIS to action McKinsey's current pricing review.
2. Introduce loadings for regional travel.
3. Immediately review the ILC framework.
4. Conduct a risk analysis urgently.

Beyond the NDIS - a vanishing tier of community mental health supports and services and a Victorian mental health sector under growing pressure**PROPOSED POLICY SOLUTIONS** (explained in further depth below):

NOTE: Policy solutions are the same as those in Section I above:

1. Release KPMG report on Victorian mental health services (completed February 2017, but not released) and use that, with recommendations below, to develop a vision and plan to ensure a comprehensive, contemporary, recovery, and community-focused mental health system in Victoria.
2. Immediate investment in a short-term 'safety net' of psychosocial rehabilitation and long-term investment in community-based services.
3. Immediate investment in the skilled and experienced community-based mental health workforce to ensure that the capacity to deliver the above safety net is maintained as well as ensuring this workforce is available to implement future visionary mental health plans in Victoria.
4. Victorian Government immediately matches the Commonwealth's 2017 psychosocial funding offer.
5. Ongoing, systematic and transparent data collection to inform future developments.

Abbreviations

AOD	Alcohol and Other Drug
DSP	Disability Support Pension
HASI	Housing and Accommodation Support Initiative
ILC	Information, Linkages and Capacity building
LAC	Local Area Coordinator
LGA	Local government Area
LHD	Local Health District
MBS	Medical Benefits Scheme
MHCSS	Mental Health Community Support Services
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PBS	Pharmaceutical Benefits Scheme
PHaMs	Personal Helpers and Mentors
PHN	Primary Health Networks
PDRSS	Psychiatric Disability Rehabilitation Support Services
SRS	Supported Residential Services
SPMI	Severe and Persistent Mental Illness

Project Background

User, provider and advocacy stakeholders with expertise gained through direct experience of the NDIS trial sites are ideally suited to collectively identify emerging and existing gaps or issues as well as provide practical and relevant recommendations to resolve these issues. The knowledge and wisdom of expert stakeholders, those with the most expertise and practice or experience-based knowledge of the NDIS rollout, form the voice and content of this report.

The project involved a three-staged process: 1. expert stakeholder identification of challenges or gaps that are existing or emerging; 2. expert stakeholder proposed best policy solutions to address these identified gaps, and 3. expert stakeholder final review of the synthesised list of proposed solutions. The project was designed to create a 'safe' environment for stakeholders to raise issues and challenges as well as to propose workable solutions. Thus it was agreed at the outset that reporting would use a collective 'voice' without direct stakeholder quotes and without stories being attributed to individuals or the organisations that they represent.

In this Victorian specific component of a broader national project, we focused specifically on the learnings, experiences and expertise of those who have been deeply engaged in the rollout of the NDIS for people with psychosocial disability in the Barwon trial site. This expert stakeholder group included a range of user, provider and advocacy organisations involved in varying aspects of the NDIS. The list of all expert stakeholder organisations who have participated in this project are named above.

Rather than an exhaustive list, the project has drawn together a prioritised list of meaningful, and relevant policy solutions identified by the expert stakeholders. These policy priorities address identified gaps and will, when acted upon, enhance the NDIS and the broader mental health system for people living with psychosocial disability in Victoria.

Methods

This Victorian-specific project focused on the rich learnings from the Barwon region NDIS trial site. It sought to understand and propose realistic and expert stakeholder prioritised solutions to any negative implications for people with mental illness both in and out of the NDIS. The following questions formed the structure of the Victorian project:

1. What does a community mental health system look like in an NDIS context?
2. What are the impacts of NDIS implementation for those in the Barwon mental health community post trial period?
3. How are people with psychosocial disability managing in the new environment?
4. What are the support pathways for those ineligible?

This Victorian component of the project also contributes to a broader national project in which close to 60 national user, provider and advocacy expert stakeholder organisations and advocates have explored and identified policy solutions to address the following gaps:

- Gaps for those eligible for the NDIS.
- Gaps for those who are ineligible.
- People who may be eligible but don't apply for the NDIS.
- Gaps in systems interface and integration.

STEP ONE

Mental Health Victoria (formerly VICSERV) and SalvoConnect invited those organisations with expertise and experience in the psychosocial component of the Barwon regional trial of NDIS to participate as expert stakeholders. Each organisational manager or CEO identified their best representative/s. The first step involved a three hour group face-to-face discussion with available expert stakeholders in Geelong. Individual telephone discussions were held with expert stakeholders not able to attend the group session and took between 25 and 45 minutes each. From these expert stakeholder discussions, the major gaps and issues were synthesised and are presented below.

STEP TWO

The summary of gaps and issues was sent electronically to all expert stakeholders. These stakeholders then proposed relevant, practical policy options or solutions that they, as experts in the field, believed could best resolve or address the gaps identified. Policy solutions were then emailed back to the University team.

STEP THREE

Proposed policy solutions provided by expert stakeholders, were collated and synthesised to remove duplicate proposals and to collapse conceptually equivalent proposals into a single representative policy solution. The list of policy solutions was then emailed back to all stakeholders for their review, and final feedback and reflections. This final step ensured that the project ended with a document that stayed true to stakeholder wisdom, knowledge and perspectives.

Stakeholder Identified Gaps & Policy Solutions

The Victorian Story – Barwon’s mental health community following the NDIS trial period

To gain a deep understanding of NDIS impact, it was critical to understand both the impact for Victorians directly engaged within the NDIS and the broader ripple impact of the NDIS upon Victorians living with mental illness who are not, and never expected to be, in the Scheme. Additionally, we examined the impact of the NDIS on the people and services who support people living with mental illness and psychosocial disability. We therefore report the gaps and challenges and the corresponding policy solutions in the following order:

1. Victorians living with severe and persistent mental illnesses not engaged in or eligible for NDIS support.
2. Victorians living with psychosocial disability who are applying for and engaging with the NDIS.
3. Family and carers’ experiences both within and beyond the NDIS.
4. The community mental health service sector, in particular the non-government or community-managed sector, who provide supports and services within and beyond the NDIS.

While our focus was on the experiences of and knowledge gained through the Barwon trial site, expert stakeholders also spoke of equivalent broader Victorian experiences and impacts.

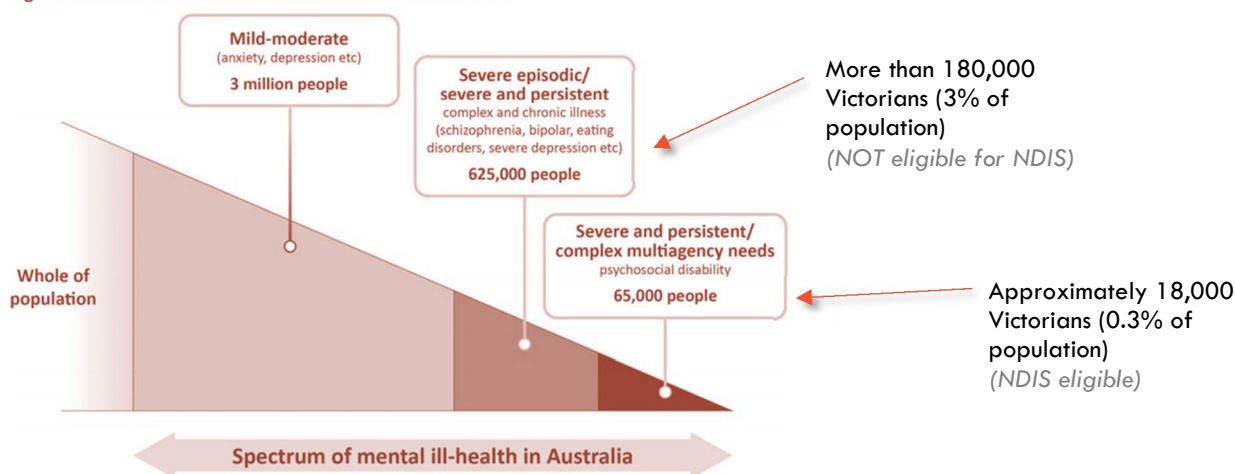
I. Experiences of, and support pathways for, Victorians living with mental illness who are NOT engaged in or eligible for NDIS support

THE GAPS AND ISSUES:

90% of Victorians living with severe mental illness are likely to be increasingly worse off.

The NDIS was only ever designed to provide support to a small percentage of people living with severe and persistent mental illness. When the NDIS is running at full capacity, an estimated 10% of people with serious or severe mental illness (approximately 65,000 people across Australia including 18,000 Victorians) will be supported within the Scheme. This means that there are 90% of Australians living with severe mental illness (around 625,000 people) who would be expected to continue to use the services and programs they currently do.^{3,7} We explored the impact of withdrawal of Victorian Government and Commonwealth funding in order to cover costs of the NDIS for the 90% of Victorians living with severe mental illness and found they were extensive. What has eventuated is precisely as was predicted and warned against three years ago in the National Mental Health Commission’s 2014 report.³

Figure 1 Annual distribution of mental ill-health in Australia



Modified from National Mental Health Commission Review, page 20³

[3] National Mental Health Commission. Contributing lives, thriving communities: Report of the national review of mental health programmes and services. Sydney: NHMC, 2014.

[7] Commonwealth of Australia (2017) Joint standing Committee on the National Disability Insurance Scheme – Report: Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition. Available from: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report

Previously available programs and support pathways are rapidly being downsized and withdrawn from 90% of Victorians living with severe mental illness in order to fund the NDIS program available to a greatly reduced number of people. This disappearing central pillar of community based psychosocial rehabilitation is the step down from clinical or acute care, previously funded by the Victorian Government. Additionally, nationally funded programs including: Partners in Recovery (PIR); Personal Helpers and Mentors (PhaMS); Day to Day Living (D2DL) and Mental Health Carer Respite Support programs are all rapidly downsizing as this funding stream also transitions to the NDIS. Stakeholders explained that the severe impact has been partially hidden for the short term because organisations have been providing non-sustainable, 'free' services. They described doing this because of a sense of ethical responsibility to people they were once funded to support and who were now being left 'high and dry'. This goodwill of the community sector is temporarily, and unsustainably, 'plugging' many service and support gaps for Victorians living with severe mental illness.

1. **Dramatic loss of services for the vast majority** (estimated to be as many as 90%) of Victorians living with severe episodic and persistent mental illness. These services include:

- a. **Services with a low threshold or minimal requirements for engagement.** These are services where people could just turn up or drop in and seek support without providing evidence, engaging in interviews, or filling in paperwork. These services provided a critical first, and sometimes only, support contact for many people living with mental illness. These drop in services were particularly important for those with the greatest barriers to gaining the support they needed – those with multiple disabilities including drug and alcohol addiction; those who are homeless; Aboriginal and Torres Strait Islander people, people from non-English speaking backgrounds and those with fear or paranoia about government bureaucracies.
- b. **Community-based services supporting recovery and psychosocial rehabilitation.** This includes a diverse range of services and programs that were run by those with expertise in mental illness (both through training and through lived experience such as peer workers) and worked in a recovery-focused way to provide psychosocial rehabilitation, engaging with and supporting people over time, to build capacity and to facilitate self-directed, strengths based ways of living with and managing their mental ill-health. These lost recovery-focused, psychosocial rehabilitation services were provided by the non-government or community-managed mental health sector.
- c. **Peer support and peer-connection.** A gap repeatedly lamented by Victorian consumers was the loss of programs that enabled them to meet and spend time with other people who shared a lived experience of mental illness. These lost programs created opportunity for, or supported people to, connect with and learn from others living with mental illness. We repeatedly heard from consumer advocacy and service provider organisations that people are feeling lonelier with less opportunity for connection and community with others with similar experiences to themselves. This is also the case for people who did have NDIS packages.

Victorians with psychosocial disability are increasingly isolated and alone, losing connection and community with others with a shared experience of mental illness

2. **Increasing use of acute and clinical services.**

Dependence on, and increased use of, clinical and acute supports as a direct consequence of the method through which the NDIS is funded is an alarming trend

Due to the reduction in recovery-focused psychosocial rehabilitation and peer-supported community-based pathways for people, stakeholders anticipated and reported starting to see an increase in the use of acute and clinical services. No longer are services available to support people to maintain wellness, or to recognise and therefore get on top of early relapse signs or warnings. Instead, support only becomes available after a person has relapsed and become acutely unwell. Identification of and addressing early relapse signs is an evidence-based and cost effective mental health practice. A plethora of evidence has been provided by the National Mental Health Commission³ regarding the cost-saving impact of investing in community-based, relapse-prevention, rehabilitation and recovery-focused programs. In their *Contributing Lives, Thriving Communities* report, the Commission said that reduction in funding for these services “may produce short-term

savings [and a quick-fix method of funding the NDIS]... but is likely to result in more severe needs in the longer term, and thus exacerbate the need for more complex support, rather than decrease system-wide demands. Once again, a significant element of this demand will fall back on Commonwealth-funded programmes such as the DSP, carers' payments, MBS and PBS, as well as on the [State Department of Health's] acute system.”³

[3] National Mental Health Commission (2014). *Contributing lives, thriving communities: Report of the national review of mental health programmes and services*. Sydney: NHMC.

Dependence on, and increased use of, clinical and acute supports as a direct consequence of the method through which the NDIS is funded is an alarming trend or prediction given that these are more expensive, 'reactive' and clinical rather than 'preventative, self-helping, peer-supported and health-promoting' pathways.

3. **Reduced sustainability of informal supports from family and carers**

Finally, as described in section III below on the impact upon family members or carers, the quality and sustainability of the informal yet critical care that Victorians living with severe mental illness receive from family, carers or friends is at serious risk, whether or not they are NDIS participants.

These critical informal support people will no longer receive the services that they previously accessed in order to maintain their own wellbeing. Burnout of carers who are supporting people with psychosocial disability of mental illness is well evidenced as is the role of respite and support services in reducing burnout. These services are ceasing in order to fund a less diverse range of support service options for a much smaller number of carers (only those whose loved one is deemed eligible for an NDIS package).

PROPOSED POLICY SOLUTIONS:

1. **RELEASE KPMG REPORT ON VICTORIAN MENTAL HEALTH SERVICES AND USE THAT, WITH RECOMMENDATIONS BELOW, TO DEVELOP A VISION AND PLAN TO ENSURE A COMPREHENSIVE, CONTEMPORARY, RECOVERY, AND COMMUNITY-FOCUSED MENTAL HEALTH SYSTEM:** Victorians living with mental illness need community-based, recovery-oriented, capacity building and relapse prevention, psychosocial rehabilitation and support services. They need peer-connection and peer-delivered programs. A long-term, funded strategy and plan for mental health services and support in Victoria needs to reflect the directions suggested in the 2015 National Mental Health Commission report on Australian mental health services to move funding from clinical to community psychosocial support services. It needs to be a mental health system that is well integrated with clinical, other health and broader community service systems. The NDIS Information, Linkages and Capacity Building (ILC) Commissioning Framework only 'tinkers' with addressing this issue in a non-sustainable, ad hoc and tokenistic way.
2. **IMMEDIATE INVESTMENT IN A SHORT-TERM 'SAFETY NET' OF PSYCHOSOCIAL REHABILITATION AND COMMUNITY-BASED SERVICES:** This immediate and potentially short-term funding is needed so that people who are ineligible for the NDIS have immediate access to 'safety net' services during NDIS implementation and development and while a longer-term plan, as described above, is planned and implemented.
3. **IMMEDIATE INVESTMENT IN THE SKILLED AND EXPERIENCED COMMUNITY-BASED MENTAL HEALTH WORKFORCE TO ENSURE THAT THE CAPACITY TO DELIVER THE ABOVE SAFETY NET IS MAINTAINED AS WELL AS ENSURING THIS WORKFORCE IS AVAILABLE TO IMPLEMENT FUTURE VISIONARY MENTAL HEALTH PLANS IN VICTORIA.** This funding will ensure that a skilled workforce is maintained through this period of upheaval and that a human resource capacity to deliver the future, visionary Victorian mental health plan remains viable.
4. **VICTORIAN GOVERNMENT IMMEDIATELY MATCHES THE COMMONWEALTH'S 2017 PSYCHOSOCIAL FUNDING OFFER:** This would to some degree go towards funding of the immediate needs outlined above, providing services that focus on people who are not eligible, and will not be eligible, to get support through the NDIS. If activated rapidly, this will also, in a small way, redress the current degrading of skills and human resources within the community mental health sector as described above.

PROPOSED POLICY SOLUTIONS (cont.):

5. **ONGOING, SYSTEMATIC AND TRANSPARENT DATA COLLECTION TO INFORM FUTURE DEVELOPMENTS:** Not only is the rapid refunding of these services and programs in line with all national and state mental health policies and plans, it also makes financial sense. Repeated anecdotal evidence suggests that this will reduce the financial impact on clinical services, AOD services, homelessness services, justice services etc. However, anecdotal evidence alone is unacceptable. Stakeholders propose that the Victorian government undertakes ongoing, systematic data collection and analysis in order to review the current service landscape in Victoria, including state and federally funded mental health services and the interfaces with universal services. This provides the knowledge required to develop a longer term, well-informed and sustainable strategy to support the 180,000 Victorians who experience complex and severe mental illness each year. Stakeholders recommend that at least the following indicators be measured: recidivism and costs to other service systems such as presentations to emergency departments, acute admissions, increased clinical intervention, crisis accommodation, justice system entry or re-entry. These and related indicators are required for an understanding of the true costs of the NDIS and the cost of not investing in community-based mental health services and programs.

II. Experiences of Victorians living with psychosocial disability who are engaging with the NDIS

THE GAPS AND ISSUES:

For Victorians living with psychosocial disability, there has been a diversity of experience and impact as described below. Stakeholders detailed the issues and challenges arising along the NDIS journey for people living with psychosocial disability themselves. Challenges arise from before a person engages with the Scheme and extend through to plan reviews and servicing of plans for those who were successful in receiving a package. However, we start by acknowledging that the NDIS has achieved very positive outcomes for some.

1. **The NDIS has been very positive for some people living with psychosocial disability.** Stakeholders agreed that for some people this was the first time that they had access to services and resources they needed. Stakeholders believed that this was most likely the case when the participant had family, carers or services who were permitted to be involved, were very involved and supportive throughout the process.
2. **Many people are not applying (choosing not to test their eligibility) or are withdrawing mid-way through the application process.** Stakeholders described a range of reasons for this:
 - a. **Lack of knowledge or understanding of the Scheme.** Stakeholders explained that many people living with psychosocial disability have no knowledge of or understanding of the Scheme, especially those who are homeless and in hard-to-reach communities including Aboriginal and Torres Strait Islander people and communities. There is no funding for assertive outreach for these hard-to-reach people (some have this through PIR – but this is not operating in the Barwon area).
 - b. **Overwhelming complexity of the process.** Stakeholders reported that Victorians living with psychosocial disability are overwhelmed by the complexity of the application process. For many people living with psychosocial disability, the process of trying to get the evidence required for application was just too hard and this led to people deciding not to, or feeling unable to, apply despite the high likelihood of being found eligible. Some people don't have the evidence, some can't get the evidence, and for others the process of trying to get the evidence required for an application was just too hard. The complexities around collecting evidence is further detailed below.
 - c. **Prohibitive costs of acquiring specialist reports.** Collecting acceptable evidence often requires people to pay for private consultants and specialist assessments to provide evidence of functional impairment and permanence of disability. These costs deterred or made applying impossible for some. In short, the poverty created by the disability was a barrier to application.

- d. **Lack of advocacy and support.** Stakeholders reported that people with psychosocial disability are often unable to navigate the complexity of the application process alone and do not have advocacy/support to do so. There were repeated examples of people commencing applications but withdrawing due to the highly stressful process.
 - e. **Lack of culturally appropriate support – particularly for Aboriginal and Torres Strait Islander people.** We heard that Aboriginal and Torres Strait Islander people living with psychosocial disability are often not applying. In large part, stakeholders said was because of a lack of Aboriginal and Torres Strait Islander workers to provide the pre-planning support in order for them to understand and engage in the Scheme in a culturally appropriate way.
 - f. **Lack of understanding that other support pathways would soon cease to exist.** Stakeholders reported that some people stated that they didn't want to apply because they were happy with current services and believed these would continue. Stakeholders found it hard to explain to these people that their current services were being transitioned to the NDIS and would not be available in the future.
 - g. **Paranoia and anxiety about the Scheme.** Some people did not apply because of paranoia and anxiety about the Scheme, such as being fearful they could lose their pension if they applied.
 - h. **Fluctuating capacity to engage in the process.** Psychosocial disability is almost invariably a fluctuating condition and thus people had fluctuating capacity to engage in the process.
 - i. **Rejecting the label or language of 'permanence'.** Stakeholders reported that many people, and younger people particularly, did not want to believe that their condition is 'permanent' and thus avoid applying because of this. Often it is the people most in need of the NDIS that 'lack insight', clinically labelled as anosognosia, who refuse to agree that they are ill or that their needs are permanent. Stakeholders highlighted the barrier created by the conflict and confusion around language. Mental health systems are driven by recovery paradigm. Recovery in this context does not equate to cure, but rather living a personally meaningful and valued life. Evidence underpins the importance and value of these hopeful messages in contrast to messages of permanence. This difference in language creates additional barriers to: the person applying; the assessment or eligibility process, and to the ultimately approved package.
3. **Many people are assessed as ineligible by NDIA.** Stakeholders reported that too many people had been assessed as ineligible for the Scheme even when they had a disability support pension, when they were engaged in programs with equivalent 'criteria', and when those with extensive mental health experience and knowledge of the person knew that they met all criteria for the NDIS. Data from NDIA also evidences that people with psychosocial disability have lower acceptance rates compared to most other conditions.⁸ When asked why, stakeholders provided a myriad of compounding reasons:
- a. **Inability to collect the extensive level of evidence required.** People living with psychosocial disability often lack the ability to collect the extensive level of evidence required. Sometimes the evidence doesn't exist due to people being very transient, not engaging with services, or rapidly changing GPs and other service providers due to their transience. Studies evidence that under 50% of people with mental illness seek treatment in any one year.⁹
 - b. **Extreme complexity of the application process.** Many people living with psychosocial disability are unable to navigate the process itself, particularly without access to support.
 - c. **Limited understanding of NDIS requirements by GPs and other evidence providers.** GPs, and other providers or services outside mental health, frequently do not understand that the NDIS is accessible for people with psychosocial disability or do not understand what detail is required in an application. GPs are experts in medical evidence. They are not experts in disability evidence. Stakeholders spoke of repeated visits to the client's GP to 'educate' them about what was required in their evidence.

[8] Commonwealth of Australia (2017). Productivity Commission Study Report - National Disability Insurance Scheme (NDIS) Costs. Available from: <https://www.pc.gov.au/inquiries/completed/ndis-costs/report>

[9] Whiteford HA, Buckingham WJ, Harris MG, et al. Estimating treatment rates for mental disorders in Australia. Australian Health Review 2014; 38(1): 80-5.

- d. **Unfair and inequitable assessment process stemming from assessors lack of understanding of psychosocial disability.** Stakeholders repeatedly described an unfair and inequitable assessment process. They provided many examples of differing outcomes for individuals with equivalent permanence and level of functional impairment.

18 case studies of Victorian's with psychosocial disability assessed as ineligible:

"You will note the lack of consistency in the reasons for rejection provided by the NDIA... current eligibility and access processes for this the fairness and equity of access that should be a cornerstone of the Scheme's design" (VICSERV, 2017)¹⁰

e. **The fluctuating nature of psychosocial disability.** Again, this inherent part of living with psychosocial disability was not understood by NDIA assessors and is not in line with NDIS language of permanence of functional impairment. Assessors lacked insight into the reality that there were likely to be meeting with a person at a time and on a day that the person was well enough to engage. Thus, judgements made from in-the-moment opinion rather than being informed by a more longitudinal lens are almost invariably going to be erroneous.⁸

f. **Denied a face-to-face assessment.** All stakeholders talked about people being refused or not offered a face-to-face appointment. Again this demonstrates a lack of understanding of the needs of people living with psychosocial disability. Direct approach by mail and cold-calling potential participants on the phone provoked anxiety and was harmful. Many people with psychosocial disability are unable to effectively articulate and advocate for their needs over the phone and they are less able to engage and include support people in the process if it is conducted over the phone. Additionally, this experience has led to anxiety and paranoia for many, and for some has led to acute relapse of illness and hospital admissions.

- g. **Lack of adequate support and advocacy at time of assessment.** Services who know people well, and have supported their mental health over time, are not allowed to speak or actively support them. Often there is no family to engage in this role. When there is, family members also described being excluded from supporting their loved one.
- h. **Anosognosia and embarrassment.** Finally, stakeholders described witnessing people who were living with very severe, ongoing functional impairments being too ashamed to admit out loud to assessors their low level of functioning or people having limited insight (anosognosia) into their disability or level of functioning. Stakeholders described a sense of frustrating impotence, not being permitted to actively support them to articulate their needs adequately because this support is deemed a commercial conflict of interest.

4. **Extensive time delays** between acceptance, planning meeting and then ultimately receiving a plan. Time delays occur at entry to the Scheme and at review. Stakeholders reported waiting up to 7 months for a review request. Delays were further exacerbated when additional specialist assessments (such as occupational therapist assessments) were identified as being needed by planners to evaluate people's functional capacity at initial assessment or as a 'proxy' for the participant's first plan. Stakeholders also talked about delays in establishing new plans due to NDIA staff catching up with a back-log of plan reviews. Stakeholders described continuing to provide unfunded services at these various points of delay for both ethical reasons and in the hope that they would be 'reimbursed' later on.

5. **Planning meetings do not align with and respect the needs of many living with psychosocial disability.** Stakeholders described the problems with one-off over-the-phone assessments for many people living with the complexity of psychosocial disability. Advocates or support people were not encouraged to attend meetings unless they were family members and many with psychosocial disability are not in-touch with family members. Policies do not allow for providers to support the participant to advocate for themselves even when the provider is witnessing a situation where the participant is overwhelmed and unable to articulate their needs. Additionally, poor or lack of understanding of psychosocial disability by NDIA staff meant that inappropriate questions were asked and inappropriate assumptions were made.

Homeless people with no housing support in their plan... people under financial guardianship orders offered to self-manage their plan... people being provided with enormous home-modification budgets that they didn't ask for or need.

[10] VICSERV. 25th August 2017. Correspondence to National Disability Insurance Agency.

6. **Ill-fitting plans for many who are eligible.** Repeatedly we heard of approved plans that did not align with the needs identified in assessment. Many examples were provided. One example was people being 'transitioned' out of a homelessness support program (now de-funded due to the NDIS) not having any accommodation or tenancy support in the plan. Another example provided by stakeholders was that planners often offered people under protective guardianship to self-manage their plans. Again, this seemed to stem from the poor mental health knowledge of planners and LACs. Additionally we heard that a lack of cultural understanding of NDIS staff has led to **culturally inappropriate plans for Aboriginal and Torres Strait Islander people** and people from other culturally diverse communities.
7. **Lack of service providers to 'action' a plan.** Stakeholders described a frequent inability to find an available provider for services in the plan. Additionally, even if those services were available, providers, carers and participants themselves struggled and often were unable to find people to provide services within the funding structure.

We heard repeated stories of ill-informed, drastic reductions made to people's plans over time.

8. **Significant reductions in revised plans.** Stakeholders described revised plans or packages being significantly reduced if people did not use a portion of the plan in the previous year. Again, this was seen as stemming from lack of understanding of psychosocial disability. If, for example, people were in prison, in hospital, or acutely unwell for a period of time in the previous year, they would have been unable to access those community-based services in their plan for a period. This should not, but did, lead to automatic deductions the following year. Additionally, stakeholders reported that **coordination of support was typically phased out** after the first plan and this demonstrated a lack of understanding of the complexity of people's needs as well as the ongoing barriers to accessing services that people with psychosocial disability often faced.

Urgent requests for plan reviews typically took months.

9. **Rigidity or inflexibility if, and when, plans need to be amended or reviewed.** Stakeholders talked about the problems with the delay in 'actioning' requests for plan reviews. These requested and standard reviews typically occurred without warning and without informing service providers or support people. Often the review would simply involve an NDIA staff calling the participant over the phone. This resulted in many people: not understanding that the conversation was a review at all; not being able to be supported by someone who knew them well and that they trusted; and, for a myriad of reasons (psychosis, paranoia, confusion, fear etc), not understanding what was being asked, and not being able to adequately advocate for themselves. Collectively this has resulted inadequate and inappropriate review plans.

PROPOSED POLICY SOLUTIONS:

1. **IMPLEMENT A SPECIALIST PSYCHOSOCIAL GATEWAY:** Urgent implementation of a specialist psychosocial gateway to the NDIS is needed. This has been recommended by the Productivity Commission's report on the NDIS costs.⁸ In line with previous Productivity Commission and other recommendations, the psychosocial gateway would be staffed by people with psychosocial disability expertise gained through lived experience, qualifications or a history of working with people with psychosocial disability. The psychosocial gateway would provide direct points of expert and accessible contact to reach out and assist and support people to overcome barriers to engaging with the Scheme, navigating the complexity of the assessment, planning and commissioning processes. Additionally, some individuals with psychosocial disability will require a prolonged planning engagement over multiple meetings in order to build the rapport and trust necessary for the development of a suitable plan. This extended engagement/planning process should also be a part of the specialised psychosocial gateway.
2. **INCORPORATE LOCAL AREA COORDINATOR AND PLANNER ROLES INTO THE SPECIALIST PSYCHOSOCIAL GATEWAY:** The Victorian (and indeed national) experience of ad-hoc assessments and ill-fitting plans is a function of poorly implemented processes, and assessors and planners who lack skills and knowledge for working with this cohort. Having planners and LACs with psychosocial disability expertise would immediately improve this major problem. LACs and planners working with people with severe mental health issues require lived experience, qualifications or experience in mental health. Again, expert stakeholders echoed a call made by other reviews. The specialist psychosocial gateway would be established by outsourcing the NDIS psychosocial disability assessment and planning functions to the psychosocial disability sector – given their established expertise. It is not acceptable for this outsourcing to go to generic organisations without psychosocial disability expertise. It is not acceptable for untrained workers to make life sustaining decisions for clients with a psychosocial disability. There is an increased risk to participant outcomes if LAC or planner roles are carried out by people without expertise in working with people with complex psychosocial disability.
3. **ESTABLISH A FUNDING POOL AVAILABLE FOR SPECIALIST ASSESSMENTS REQUIRED BY NDIA:** Primary health providers e.g. GPs, psychiatrists, and clinicians, require funding to provide the time needed to understand, complete and provide the complex documentation required for people with psychosocial disability to meet the eligibility criteria. The specialist psychosocial gateway described above needs to have funds that people can draw on to pay out-of-pocket expenses for assessments that they may require as part of demonstrating eligibility. This would ensure that these required assessments do not present an inhibitive cost barrier to people applying.
4. **FUNDED ASSERTIVE OUTREACH FOR HARD TO REACH AND HARD TO ENGAGE POPULATIONS:** Put in place and fund assertive outreach schemes for people living in: supported residential services; rooming and boarding houses; other forms of insecure accommodation, or registered with specialist homelessness services (SHS). This scheme needs to be developed in conjunction with Victorian organisations that are most likely to be in contact with populations who are not currently aware of, understand, or willing to access NDIS without this form of proactive assistance. Plans for the development and extension of assertive outreach should be informed by a review of the effectiveness of existing ILC projects funded to facilitate access to NDIS by people with psychosocial disability. It could be provided through the specialist psychosocial gateway. We note that the Victorian Government has put resources into Supported Access Teams that will work with providers to engage with eligible clients who are hard to reach during transition.

[8] Commonwealth of Australia (2017) Productivity Commission study report National Disability Insurance Scheme (NDIS) Costs. Canberra.

PROPOSED POLICY SOLUTIONS (cont.):

6. **DESIGN AND DELIVER NDIS PROCESSES AT THE COMMUNITY LEVEL TO ENHANCE ACCESSIBILITY AND CULTURAL RELEVANCE OF NDIS:** Rapid establishment of specific strategies for Aboriginal and Torres Strait Islander people living with psychosocial disability, in partnership with the Aboriginal-controlled and run organisations working with those communities and families, is needed. Aboriginal people living with psychosocial disability and potentially accessing the NDIS need to be able to access Aboriginal staffed supports and services. These strategies are equally critical for NDIS relevance to culturally and linguistically diverse (CALD) communities.
7. **REVIEW AND REDUCE THE OVERWHELMING LEVEL OF EVIDENCE REQUIRED FROM APPLICANTS:** Review of the overwhelming evidential requirements of the NDIS with an understanding of the particular complexities for many living with psychosocial disability: fluctuating levels of functioning; transience and high rates of homelessness; disconnection to service systems and thus 'evidence'; anosognosia; poverty, and the lack of connection to family and carer support of many. The specialist psychosocial disability gateway would incorporate specific strategies to support these people with the burden of evidence needed. It is also recommended that existing assessments and other documentation from current support providers (currently excluded as evidence) be used to support the articulation of individual consumer's needs, with their consent. A formal agreement with public mental health services to provide current or recent clients (discharged in last 12 months) with the documentation they need to demonstrate eligibility would assist. This would require specialist gateway staff to have or establish relationships with people's GPs and public health services (under appropriate protocols for information sharing).
8. **INCLUDE TIMEFRAMES FOR ACTIONS WITHIN LAC AND PLANNER KEY PERFORMANCE INDICATORS:** Development of an outsourced specialist psychosocial gateway, with skilled planners and LACs who have clear key performance indicators around the timeliness of their actions, would address this issue.
9. **IMMEDIATELY CEASE OVER-THE-PHONE ASSESSMENTS AND PLANNING MEETINGS:** Only face to face assessment and planning meetings are acceptable for people with psychosocial disability.
10. **ENSURE ADVOCATES AND SUPPORTS ARE INVITED AND INCLUDED AS PART OF STANDARD, REQUIRED PRACTICE:** All participants are to be encouraged to have the support person/people of their choice to attend planning meetings. Moreover, while it is acknowledged the person accessing the NDIS must have the opportunity to speak for themselves without interference from others, it is also acknowledged that on many occasions the participant, due to anxiety or other reasons, may not be able to effectively advocate for themselves in the planning meeting. Therefore, as proposed above, it is recommended that planning meetings for participants with psychosocial disability are facilitated by LACs and planners who are skilled in mental health and carer engagement.
11. **ESTABLISH AN EVIDENCE BASE TO ENHANCE NDIA CAPACITY TO UNDERSTAND THE DIFFERENCE BETWEEN THOSE WHO NEED MAINTENANCE SUPPORT AND THOSE WHO WOULD BENEFIT FROM SUPPORTS TO IMPROVE FUNCTIONING.** The NDIS provides for both core supports and capacity building opportunities, however the latter is rarely included within plans and the process of identifying who would benefit from capacity building resources appears ad hoc. Addressing this problem requires the establishment of an evidence base that can identify those cohorts that can be assisted to improve their functioning, and those who need assistance with maintenance/support needs. Many have a combination of functional improvement AND maintenance needs. Once established, this evidence base could be linked to a standardised, validated assessment tool.
12. **ESTABLISH A BETTER ASSESSMENT TOOL.** Establishing a more validated assessment tool for functional impairment for people with psychosocial disability, to replace the current tick-box form, would enhance the assessment process.

III. Family member and carer and experiences

THE GAPS AND ISSUES:

PREVENTED OR NOT ABLE TO SUPPORT THEIR LOVED ONE THROUGH THE NDIS PROCESS

1. **Family and carers have typically not been informed about or included in their loved one's assessment and planning processes.**
2. **The NDIS does not have a broad understanding of who might be a participant's family, carer or other significant support persons.** These critical informal supports are often 'hidden' and include children or community members in Aboriginal and Torres Strait Islander and culturally diverse communities. Without this understanding, these informal yet critical supports are excluded from the process.

We heard repeated stories of family stress and distress in relation to navigating the system, the bureaucracy, paperwork, and gathering evidence such as functional assessments for their loved one
3. **Families and carers are overwhelmed by the complexity of the application process** for their loved one. The significant workload involved in seeking and requesting evidence, completing paperwork, coordinating services, chasing up of clinical services and coordinating with the NDIA during through the NDIS access and planning processes has been a major stressor for families and carers. Stakeholders described these concerns often being raised in community consultations and through direct feedback.

CARERS AND FAMILY MEMBERS ARE NOT HAVING THEIR OWN NEEDS MET

4. **Carer support services are only included in an NDIS package if the participant requests funding for such services.** When family members or carers are not included in the assessment and planning stages, their needs are typically not addressed. Even when they are included, for participants with a psychosocial disability, there are many barriers to understanding or acknowledging the caring role taken on by family and friends. These include stigma; a blurring of family roles and responsibilities; or simply different perspectives on how a person is supported. Discussion of what supports are provided and what burden is taken on by families and friends to provide the support required are straining these relationships.
5. **Most families and carers are unaware that they can be supported through the plan** of the person they support. They are unaware that they can submit a Carers' Statement and that they can request a separate meeting with the planner.
6. **Supports and services available to families and carers through the NDIS severely limited.** Within the NDIS, there are not the resources, scope or capacity to deliver the services required to adequately support families and carers. Supports and services available to families and carers through Individual Support Packages and the funding associated with the ILC is severely limited. There is very little scope for the emotional, social and physical wellbeing of families and carers.

Evidence-based carer programs, established to assist them to maintain their own and their loved-one's wellbeing, are closed to fund the NDIS.
7. **Funding previously available to support carers to sustain their own wellbeing is ceasing as it is transferred to the NDIS.** This means that all of the crucial carer support programs and services for those supporting the vast majority (90%) of Victorians living with severe mental illness will no longer exist. These, defunded, primarily federally initiated carer programs, were established on strong evidence that investing in family and carers who provide informal and critical supports to those living with mental illness, ultimately reaps both systemic financial and family wellbeing outcomes. The decommissioned services also include services and supports for children carers of parents living with mental illness.

PROPOSED POLICY SOLUTIONS:

1. **TRAIN PLANNERS IN CULTURALLY AWARE, FAMILY-INCLUSIVE PRACTICE:** Local Area Coordinators and planners are to be given cultural awareness training to understand the diversity of carer/family/community relationships that exist within Australian society. There are existing training resources to support development of family inclusive practices that could be tailored to the specific of the NDIS. Alternatively, experts in these areas could be engaged to provide training.
2. **REQUIRE ACTIVE ENCOURAGEMENT OF FAMILY AND CARER INCLUSION AT CONSULTATIONS.** This also requires LAC and planner training to understand how to do this whilst respecting a client's choice and control. NDIA do not currently undertake a comprehensive assessment of the client to elicit information regarding the diverse range of possible family/community/carer supports, and currently it is not part of their role. Policy changes need to occur in this area including directives regarding assessment and planning processes and, as above, expert-delivered training provided.
3. **ENHANCE CARER AND COMMUNITY EDUCATION PROGRAMS.** NDIA should develop a program for communities, carers and family members that combines promotion and education of the NDIS as well as rights-based training, so that people in care relationships with NDIS applicants and participants are aware of the Scheme, and how to make it work best for the person they are in a care relationship with. These programs are particularly needed for Aboriginal and Torres Strait Islander and other culturally diverse people and communities. Programs should be developed and run in partnership with those communities to ensure they are culturally appropriate.
4. **IMMEDIATELY IMPLEMENT A FULLY FUNDED CARER STRATEGY SEPARATE FROM THE NDIS.** Due to the complexity of carers being able to advocate and articulate their own needs within the same context as advocating for the needs of their loved one, as described above, carer supports should be clearly separated from the consumer assessment and planning process of NDIS. The Department of Social Services needs to reinstate funding for Mental Health Carer Support and Respite, and ensure that eligibility criteria include all people in care relationships with someone with severe and complex mental illness – not just those who are NDIS eligible. More broadly, it is important to situate this within policy on care and caring in Victoria that includes better systems for identification of people in caring relationships. Carer services need to be enhanced and expanded beyond pre-NDIS levels. There are clear economic reasons to do this. The recent Mind & University of Queensland Economic Evaluation of Mental Health Caring in Australia evidences the amount and nature of unpaid care, and the inadequacy of the extent of pre-NDIS supports for carers of people living with mental illness and psychosocial disability.

IV. Community mental health services and organisations

THE GAPS AND ISSUES:

Two major factors are placing great pressure on the Victorian community mental health sector: issues inherent with the unsustainable pricing structures within the NDIS, and the decommissioning of Victorian Government and Commonwealth programs in order to fund the NDIS.

ENGAGING WITH, AND PROVIDING SERVICES AND SUPPORTS WITHIN THE NDIS:

The non-government or community-managed mental health system in the Barwon region is rapidly downsizing and practicing in unsustainable and risky ways to try and survive within the NDIS pricing system. All organisations engaged in the NDIS talked about calculating timeframes before they needed to withdraw from the NDIS program.

1. **Collapsing, merging and electing not to provide services under the NDIS.** Smaller Victorian non-government or community-managed organisations described collapsing and merging. A stark example is

Pathways, the main community mental health provider in the Barwon NDIS Trial Site that went into voluntary administration last year.¹¹ As well as organisations collapsing and merging, they also repeatedly talked about waiting to see how things go before offering services through the NDIS or choosing not to engage with the NDIS at all. In combination, this is resulting in loss of organisations, programs and services developed to meet the needs of local communities and appears to be in direct contrast to national policies and directions promoting a localised approach to service development (e.g., the PHN approach).

2. **Running at a loss.** All non-government organisations described running at a loss that was not sustainable. They all described paying their NDIS service delivery staff more than 'allocated' within the NDIS pricing structure in order to maintain staff quality, mental health knowledge and skill. They all described offering and providing 'free' services to clients because they were not in the NDIS and no other funded services were available. They all described providing more services to clients than was allocated in NDIS approved plans to 'plug' gaps in service plans, and, as said above, covering the costs for these 'extensions' of service while understanding this was not sustainable long-term.

All organisations described covering these additional costs by drawing on reserves and donations with an understanding that there was a time limit before the organisation would 'step away' from engagement with the NDIS. The larger organisations had established that they could 'carry' this financial burden for two years; for others the timeframe was much shorter.

3. **Bending the rules to survive.** Stakeholders invariably described 'bending the NDIS rules' to survive financially, or to extend the time before they would withdraw from the NDIS. Stakeholders described the impact that this 'rule-bending' had on their culture and morale with a growing sense of need for secrecy rather than cross-organisational connection, collaboration and sharing (hiding clearly questionable, but deemed essential-to-survival, practices).
4. **Losing a talented mental health workforce.** Even with their commitment to 'top up' staff pay-rates as described above, all organisations described the distress of 'shedding' talented, well trained staff that they had invested time and resources in building and training.
5. **Staff training, support and supervision reduced to risky levels.** All stakeholders described radically changing, or ceasing in some cases, staff induction, orientation, supervision, support and training. They believed that supervision had been reduced to remote and 'risky' levels. They had drastically reduced once regular face-to-face supervision sessions to either no regular face-to-face staff support, or group-based, brief, monthly supervision at best. Staff induction or orientation and training were now typically run online with minimal capacity to ensure they were completed. NDIS service staff now operate remotely, using their personal vehicles to travel directly from their home to clients and home again to reduce time and costs. Staff thus had rare direct contact with the organisation. Again, to try and keep to the NDIS pricing structures, staff conducted minimal documentation, electronically and on the go.

The opportunity for organisations to connect, collaborate and build integration has been lost

6. **Lamenting the loss of a person-centred model for this new business driven model.** All stakeholders believed that a very different culture is now driving the community managed or non-government mental health system in Barwon, with a business model rather than people at the centre. Funding, and thus opportunity, for organisations to connect, collaborate and build integration has been lost. This also impacted on capacity to develop relationships and partnerships beyond the community mental health sector, such as with Aboriginal organisations and communities.

[11] Neami National, (2017) Learnings from Pathways: A retrospective analysis of one business failure in the Barwon NDIS Trial. Neami National.

BEYOND THE NDIS - A VANISHING TIER OF COMMUNITY MENTAL HEALTH SERVICES:

All Victorian stakeholders highlighted the loss of a central pillar of the mental health service delivery system in the Barwon region due to funding reallocation to the NDIS. This disappearing or vanished critical tier of support is the step down from clinical or acute care; the community-based psychosocial rehabilitation service system previously funded through the Victorian Government. Additionally, nationally funded programs including Personal Helpers and Mentors (PhaMS), Day to Day Living (D2DL), and Mental Health Carer Respite Support programs are all rapidly downsizing as this funding stream also transitions to the NDIS. While most consumers who use these programs are not eligible for NDIS packages, all funding and thus service delivery has been withdrawn to fund the NDIS. This lost suite of services and programs includes a diverse range of recovery-focused services, low-threshold to access services, and peer-support and peer connection services. They are further detailed in Section I above. Alongside the loss of services and programs is a rapid loss of a skilled workforce.

The loss of psychosocial rehabilitation services is greater in Barwon, Victoria than other states and territories due to the Victorian Government transferring almost all of state psychosocial funding to the NDIS. This disappearing tier is only 'covered' in a tokenistic, unsustainable way within the Information, Linkages and Capacity Building (ILC) Commissioning Framework of the NDIS.

Because of State and Federal Government syphoning of psychosocial rehabilitation and support funding, Victorians living with mental illness are facing a mental health service system that is rapidly shifting in the opposite direction to all current national and international mental health policies and plans. These policies and plans call for increased community-based, recovery-oriented, early intervention services and supports because that will, over time, reduce the financial burden of more acute services as well as social security costs. "The Independent Hospital Pricing Authority found that... the average \$10,000 spent on one person's hospitalisation of nine days could enable a community mental health service to provide support to a person for a full year."³ (page 28)

Victorians living with mental illness are facing a mental health service system that is rapidly shifting in the opposite direction to all current national and international mental health policies and plans.

Beyond financial benefits, this international agenda stems from a social justice and human-rights perspective – that people living with mental illness and psychosocial disability have the right to supports needed to live contributing and thriving lives within their communities of choice. Tragically, while these perspectives underline the purpose of the NDIS, actual implementation is resulting in the polar opposite reality for most.

The post NDIS mental health system, particularly for those ineligible for the Scheme (a number far exceeding the number of people who are or will be eligible) only provides acute, clinical and crisis-point services. The well-evidenced and multiple benefits of investing in non-clinical, community based services have been overlooked or dismissed in the short-sighted method of funding the NDIS – reducing and defunding community-based services and supports designed specifically to meet the needs of people living with severe mental illness.

[3] National Mental Health Commission (2014). Contributing lives, thriving communities: Report of the national review of mental health programmes and services. Sydney: NHMC.

PROPOSED POLICY SOLUTIONS:

NOTE: These policy solutions below are the same as those proposed in Section I - Experiences of, and support pathways for, Victorians living with mental illness who are not eligible for NDIS support

1. **RELEASE KPMG REPORT ON VICTORIAN MENTAL HEALTH SERVICES AND USE THAT, WITH RECOMMENDATIONS BELOW TO DEVELOP A VISION AND PLAN TO ENSURE A COMPREHENSIVE, CONTEMPORARY, RECOVERY, AND COMMUNITY-FOCUSED MENTAL HEALTH SYSTEM IN VICTORIA:** Victorians living with mental illness need community-based, recovery-oriented, capacity building and relapse prevention, psychosocial rehabilitation and support services. They need peer-connection and peer-delivered programs. A long-term, funded strategy and plan for mental health services and support in Victoria needs to reflect the directions suggested in the 2015 National Mental Health Commission report on Australian mental health services to move funding from clinical to community psychosocial support services. It needs to be a mental health system that is well integrated with clinical, other health and broader community service systems. The NDIS Information, Linkages and Capacity Building (ILC) Commissioning Framework only ‘tinkers’ with addressing this issue in a non-sustainable, ad hoc and tokenistic way.
2. **IMMEDIATE INVESTMENT IN A SHORT-TERM ‘SAFETY NET’ OF PSYCHOSOCIAL REHABILITATION AND COMMUNITY-BASED SERVICES:** This immediate and potentially short-term funding is needed so that people who are ineligible for NDIS have immediate access to ‘safety net’ services during NDIS implementation and development and while a longer-term plan, as described above, is planned and implemented.
3. **IMMEDIATE INVESTMENT IN THE SKILLED AND EXPERIENCED COMMUNITY-BASED MENTAL HEALTH WORKFORCE TO ENSURE THAT THE CAPACITY TO DELIVER THE ABOVE SAFETY NET IS MAINTAINED AS WELL AS ENSURING THIS WORKFORCE IS AVAILABLE TO IMPLEMENT FUTURE VISIONARY MENTAL HEALTH PLANS IN VICTORIA.** This funding will ensure that a skilled workforce is maintained through this period of upheaval and that a human resource capacity to deliver the future, visionary Victorian mental health plan remains viable.
4. **VICTORIAN GOVERNMENT IMMEDIATELY MATCHES THE FEDERAL GOVERNMENT PSYCHOSOCIAL FUNDING OFFER:** This would to some degree go towards funding of the immediate needs outlined above, providing services that focus on people who are not eligible, and will not be eligible, to get support through the NDIS. If activated rapidly, this will also, in a small way, redress the current degrading of skills and human resources within the community mental health sector as described above.
5. **ONGOING, SYSTEMATIC AND TRANSPARENT DATA COLLECTION TO INFORM FUTURE DEVELOPMENTS:** Not only is the rapid refunding of these services and programs in line with all national and state mental health policies and plans, it also makes financial sense. Repeated anecdotal evidence suggests that this will reduce the financial impact on clinical services, AOD services, homelessness services, justice services etc. However, anecdotal evidence alone is unacceptable. Stakeholders propose that the Victorian government undertakes ongoing, systematic data collection and analysis in order to review the current service landscape in Victoria, including state and federally funded mental health services and the interfaces with universal services. This provides the knowledge required to develop a longer term, well-informed and sustainable strategy to support the 180,000 Victorians who experience complex and severe mental illness each year. Stakeholders recommend that at least the following indicators be measured: recidivism and costs to other service systems such as presentations to emergency departments, acute admissions, increased clinical intervention, crisis accommodation, justice system entry or re-entry. These and related indicators are required for an understanding of the true costs of the NDIS and the cost of not investing in community-based mental health services and programs.

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