



mental health

community coalition ACT

To:

Minister for Health
The Hon Sussan Ley MP

Minister for Social Services
Hon Christian Porter MP

Assistant Minister for Disability Services
The Hon Jane Prentice MP

ACT Minister for Disability
Chris Bourke MLA

ACT Minister for Health
Simon Corbell MLA

Cc:

Senator for ACT
Senator Zed Seselja
Liberal Party of Australia

Senator for the ACT
Shadow Minister for Mental Health
Senator Katy Gallagher
Australian Labor Party

Member for Fraser, ACT
Hon Dr Andrew Leigh MP

Member for Canberra, ACT
Ms Gai Brodtmann MP

Candidate for Fenner, ACT
Mr Robert Gunning
Liberal Party of Australia

Candidate for Senator for ACT
Dr Christina Hobbs
The Greens

Dear Minister

SUBJECT: Urgent action required - NDIS and people with psychosocial disability

We are writing in our capacity as the peak body for community managed mental health service providers in the ACT, and therefore on their behalf. We are in constant contact with our 49 members, the majority of whom are not-for-profit (NFP) mental health service providers.

The National Disability Insurance Scheme (NDIS) has the potential to improve the lives of people with disability; as such Australia is a leader in its commitment to properly fund the support needs of people with disability. It is without question that our members, and by extension consumers and carers, want the NDIS to succeed.

However, our members are also telling us that despite their best endeavours, they are deeply concerned about their ability to offer sustainable, safe, quality support services to people with mental illness and psychosocial disability (PSD) within the NDIS framework.

They report to us that aspects of the framework – particularly the financial aspects – do not adequately support people with PSD, and that although full scheme rollout is imminent,



there remains a lack of clarity in many areas that directly impact on community mental health services. In short, the NDIS framework reflects a lack of understanding around the particular requirements of effective support for people with PSD.

We are recommending urgent action in six key areas of concern, specifically in relation to how the NDIS applies to PSD:

- 1. The NDIS should be underpinned by a funding and pricing model that recognises and supports provision of reasonable and necessary support services to eligible people, including services tailored to the specific needs of people with PSD at all levels of complexity**
- 2. Identify and address barriers to access and appropriate support specific to PSD**
- 3. The implementation processes for the NDIS are creating impediments to efficiency and service delivery**
- 4. Investment and certainty in programs for people not eligible for NDIS Individual Funding Packages (IFPs) but still requiring support services**
- 5. Ensuring carers of people with PSD are no worse off**
- 6. Safety and risk management policies need to be implemented**

The important reasons for these concerns are explained in more detail in **Attachment 1** to this letter. In writing this letter we also recognise that some of the concerns raised are shared by members of the general disability community.

As a whole of jurisdiction trial site, the ACT has early experience of the impacts of the NDIS framework on PSD services. Through our involvement with Community Mental Health Australia – the alliance of State and Territory community mental health peak bodies – we know that our concerns are shared more broadly across Australia. The report from the Barwon trial site in Victoria (*Learn and Build in Barwon*, June 2015, Psychiatric Disability Services of Victoria) raises issues that are typically being experienced by other trial sites.

Ramifications from these issues are starting to be reported in the media. Most recently, there was extensive coverage of the imminent closure of 'Pathways', a respected service provider in Geelong. This service supports 366 people with mental illness and employs 144 staff. See, for example, *Federal Election 2016: suicide warning over late NDIS 'bungling'*, (The Australian, May 17 2016.)

Our members have experienced many examples of the changes taking place in service provision that reduce confidence that the NDIS will deliver effectively for people with PSD. One ACT organisation has had to completely restructure to remain viable under the NDIS. In doing so, they stopped offering a respected and effective independent living program in favour of a supported residential program. Participants displaced as a result of this

restructure have been transitioned to other organisations' services, but this has left receiving organisations without capacity to meet growing demand. In turn, the receiving organisations are now left with the uncertainty of whether it remains viable for them to deliver these services in the medium to longer term. We are also getting reports of a lack of NDIS registered psychologists in the ACT.

Organisations tell us that staff roles have been restructured to lower Award classifications because this is required to ensure an organisation can cover all employer obligations within the NDIS financial framework. However, they are unable to attract suitable applicants at these lower rates of pay. Experienced, qualified and dedicated staff are leaving for other job offers in light of lower pay, poor career progression prospects and job insecurity.

Even as we finalise this letter more significant changes have been announced without adequate lead time, training or detailed information – the introduction of "My First Plan", a new provider portal and user registration process, new service booking processes, and the closure of the existing participant and provider portals.

Our members (and other organisations) are consistently telling us that organisational sustainability under the NDIS is only possible if an organisation has the ability to cross subsidise from other activities or funding. It is not reasonable or sustainable that the NDIS financial framework place organisations in this position.

The issues we raise cross both Commonwealth and State/Territory government jurisdictions, making it imperative for all levels of government to communicate effectively and work cooperatively to ensure the viability of the scheme. As a peak body we have been raising these and other concerns with the National Disability Insurance Agency (NDIA) and ACT Government on behalf of our members since the beginning of the trial in the ACT. While all parties have been collaborating and working hard to implement the NDIS, the concerns highlighted in this letter remain unresolved despite best efforts.

When it was introduced, the Government promised that 'no one will be worse off' under the NDIS. It also stated that the NDIS would facilitate a better life for people with disability, and give them more choice and control in the services they receive and the way they live. In our experience, the NDIS works well for only some of the people who are eligible, and there is a risk that many others will 'fall through the gaps'.

The majority of the issues highlighted in this letter emanate from shortcomings in the NDIS financial model and support catalogue, which in turn reflects the general lack of understanding of PSD and how to provide reasonable and necessary support for people with PSD.

Without adequate support, people with PSD become unwell and the cost to society is much greater in terms of withdrawal from economic activity; increased demand on informal supports, including family members ceasing work to take on caring roles; and increased demand for the more costly parts of the health system (including forensic mental health).

This letter is not motivated by a reluctance to change, improve or by the possibility of for-profit service providers entering the sector. Rather it is driven by concern about the needs of people with PSD and what we see as poorly managed risks to their recovery, wellbeing and social and economic inclusion.

The misalignment of NDIS prices with the actual costs of quality community managed mental health services is substantial, and places people with mental illness and PSD at risk. While we agree that there is always room for improvement, 'community managed services provide

a critical gateway for people affected by mental illness to live valued lives in the community'. Further, '... [there is] also a strong and growing evidence base [in support of this] in addition to people's lived experience of recovery' (*Taking our place – Community Mental Health in Australia* pp.12-14, 2012).

Unless action is taken to resolve the concerns outlined above, what our members and other jurisdictions are experiencing leaves us very concerned that the NDIS will fail to deliver on its economic and social objectives. Without redress, the NDIS will not be able to facilitate longer term savings resulting from people with mental illness and PSD being socially and economically engaged, being supported to manage their episodic increase and decrease in needs, and being kept out of hospital.

Yours faithfully,



Simon Viereck
Executive Officer
Mental Health Community Coalition ACT (MHCC ACT)

27 June 2016

This letter is endorsed by the following organisations:

ACT Council of Social Services	Northside Community Service
ACT Mental Health Consumer Network	Richmond Fellowship
Belconnen Community Services	Schizophrenia Fellowship of NSW Inc (ACT)
Carers ACT	St Vincent de Paul Society - Canberra/Goulburn
Mental Health Australia (MHA)	Woden Community Service
Mental Health Foundation ACT	Women's Centre for Health Matters
MI Fellowship	Youth Coalition of the ACT

Attachment 1

We are recommending urgent changes to the NDIS in order to safeguard the lives of people living with mental illness and PSD – some of Australia's most vulnerable people.

Change needs to be enacted in the following six key areas as a priority:

1. The NDIS should be underpinned by a funding and pricing model that recognises and supports provision of reasonable and necessary support services to eligible people, including services tailored to the specific needs of people with PSD at all levels of complexity
 - a. The NDIS model effectively halves the hourly rate paid for a range of typical PSD supports as compared to the previous system, and is leading to PSD services being withdrawn or closed and a downgrading of workforce quality.
 - b. Only those people with severe and enduring mental illness who have the most complex needs - approximately 10-12% - are estimated to be eligible for IFPs. The 2011 Productivity Commission's Disability Care and Support report that helped cement the introduction of the NDIS, references existing and significant workforce shortages in community mental health. It notes the more specialist and highly qualified nature of this workforce compared to the disability workforce, and that this workforce is misunderstood and undervalued.
 - c. Our members have worked hard over decades to increase provision and quality of evidence-based recovery-focussed community based support following the deinstitutionalising in the 1980s and 1990s. It would be wrong if the NDIS took service provision and workforce quality backwards.
 - d. For organisations to offer a wide variety of quality sustainable services they need to be able to maintain back office functions; train, develop and supervise staff; develop innovative and specialist services; and be flexible enough to respond quickly to unpredictable deterioration in mental health status that leads to escalation of needs and crises.
 - e. A financial model with correlation between prices paid and actual costs of service delivery, will ensure a full range of services by reducing the incentive for organisations to 'cherry pick' only the better funded supports.
2. Identify and address barriers to access and appropriate support specific to PSD
 - a. The barrier imposed by the deficits-based language and entry requirements of the NDIS is real to many people and cannot be overstated. After years of focus on hope, recovery and a person's strengths, it is not simply a case of 'getting used to' the language.
 - b. The nature of mental illness in itself can be a barrier to entry and appropriate support – PSD is often an episodic 'invisible' disability that means needs are not evident to others, and people often lack the motivation and cognitive ability to access and generally engage with the scheme. The recent announcement of the My First Plan process is illustrative of this: many people with PSD do not have access to, cannot use, or refuse to use, a computer – even more so if the use or website is obviously connected with government.
 - c. Some people do not recognise they need support or that support is available to them. This has implications for themselves and the people who offer informal support (families, friends, carers).
 - d. Due to the episodic nature of PSD, people's decision making ability can vary. The implications from this in terms of initial engagement, planning, plan implementation

- and management, review, assessing progress and long term engagement are complex, and risk mitigation around all these needs to be tailored to PSD.
- e. People with PSD and complex needs require sophisticated psychosocial interventions as part of their daily supports. As noted above the NDIS pricing framework doesn't support a workforce with the capability to deliver such interventions.
 - f. Self-managed Individual Funding Packages (IFPs) are particularly challenging - both for the risk that a person may have capacity whilst making the plan and then become unwell and unable to manage the plan as well as was originally expected; and/or in that impaired capacity at the time of planning results in their right to choice and control being curtailed for the duration of the plan. This poses risks both to them and their carers.
3. The implementation processes for the NDIS are creating impediments to efficiency and service delivery
- a. Planning and funding is needed from governments for a transition period that will take several years. The NDIS is a radical change in the provision and purchasing of services, requiring enormous amounts of (largely unfunded) work both to engage and prepare people with PSD, and to implement restructured business models.
 - b. NDIS implementation is taking place in the midst of other significant mental health and wider health sector funding and service delivery reforms – thereby creating layers of uncertainty and change that need to be managed despite the lack of clarity and alignment in timeframes.
 - c. Backlogs in NDIA processes and systems are already leading to cases where State/Territory funding is cut to an organisation before NDIS funding is available. As a result some organisations are carrying tens of thousands of dollars of liabilities for support provided, which are not always fully refunded.
 - d. Organisations are being told to reorient everything they do to a market mindset, yet the administration of the scheme does not facilitate an effective market: prices are fixed, supports are strictly defined, administrative burdens are being increased, information gaps abound, changes are constantly being made, and communication around all the above is often not available in a uniform or timely manner.
 - e. A good example of the previous point is the recent announcement to the sector that not only are the NDIS Portals being closed for the last two weeks of June, but the new portals being opened from 1 July will require organisations and participants to undertake a new registration process and training in the new system.
 - f. Full Scheme implementation needs to be based on an evaluation of the experiences in trial sites, with the scheme adjusted accordingly. Publication of evaluation results and learnings would provide a useful resource for all involved.
 - g. Consultation timeframes on aspects of the scheme development are often inadequate for deep engagement; and subsequent decisions reflect little change in response to input. There are many examples of this, but the processes around the Information, Linkages and Capacity Building (ILC) framework and the recent pricing review stand out. In the case of the new "My First Plan" process we are not aware of any consultation.
 - h. Uncertainty remains around funding, capacity and other operational matters more broadly. Indeed, the Community Council for Australia (CCA) recently wrote to political candidates across the country asking eight questions on how they plan to support the Not for Profit sector, two of which are to do with ending funding uncertainty.

4. Investment and certainty in programs for people not eligible for NDIS IFPs but still requiring support services
 - a. There is an urgent need for clarity for the approximately 90 per cent of people with severe and enduring mental illness who will not be eligible for IFPs. Full Scheme implementation starts on 1 July 2016 which means that cessation of NDIS 'in-scope' program funding is imminent, but not everyone currently supported through these programs is being found eligible for IFPs – continuity of support arrangements for these participants remains unclear, at least in part.
 - b. Scores of people in the ACT require PSD support services on a non-permanent basis each year. There is no clarity about how this support will be provided in the future.
 - c. Investment in the Information, Linkages and Capacity Building (ILC) component of the NDIS needs to go well beyond the meagre amount allocated nationally if it is to fulfil its stated aim of providing baseline support infrastructure that keeps to a minimum the number of people needing IFPs.
 - d. We still don't actually know what supports the ILC will deliver for people with PSD. In the ACT the only mental health service identified as an ILC service is the Volunteering ACT *Connections Volunteers* 'buddy' program.
 - e. Without clarity and certainty over funding it is difficult for organisations to provide services and increases the risk of people 'falling through the gaps'.
5. Ensuring carers of people with PSD are no worse off
 - Carers are directly impacted by whether the person they care for will be eligible for the NDIS and/or choose to engage with the Scheme.
 - The needs of carers, including young carers, and how they will be impacted by the NDIS rollout have not been adequately examined. Carer needs have to be better addressed in NDIS plans to ensure that carers are able to keep caring for their loved ones and be socially and economically engaged in the community.
 - Planners must examine the consumers' needs in relation to what is being defunded from carer support services but consumers are inadvertently not planning for – e.g. domestic assistance and support workers who can step in when carers are unwell, working etc.
 - Funding for respite and some carer support services are considered in-scope for NDIS, yet access to respite and carer focussed supports is seriously curtailed in NDIS plans.
6. Safety and risk management policies need to be implemented
 - a. Quality and safeguards standards need to be clarified and implemented – indeed these should have been in place when trials began.
 - b. The lack of a quality and safeguards framework poses serious risks to participants as well as to workers who are entering participants' homes with very limited information about them or any risk factors.
 - c. The recent changes to the NDIS Portal for consumers is a case in point. Many people with psychosocial disability will need support to engage with MyPortal. There is no funding or capacity for community service providers to help them with this. If somehow support coordinators are to help people with accessing MyPortal, they may be asking participants for their MyGov login details in direct contravention of the MyGov Terms of Use (see Version 2016/3.1 – section 2.1). This is obviously an unacceptable position and level of risk to impose on service providers.
 - d. The NDIS financial framework makes meeting existing standards and industrial relations requirements very difficult to impossible.

