



tandem

representing Victorian
mental health carers

**Submission to the Inquiry into the National Disability Insurance Scheme Savings Fund
Special Account Bill 2016**

A Submission by Tandem Inc.

Representing Victoria's Mental Health Carers

October 2016

About Tandem

Tandem is the Victorian peak body representing carers of people experiencing mental illness or emotional distress. A carer may be a family member, partner, nominated person or friend who supports a person with this experience.

Our mission is to ensure that the importance of the contribution, expertise, experiences and needs of families and other carers for people living with mental illness is recognised, and that these needs are addressed. Families and other carers of people with mental health issues will be partners in treatment, and service delivery, planning, research and evaluation. The lived experience of families and other carers will be key drivers of policy and program formation at both the individual and systemic level.

Our principle areas of work:

- Promote and advocate for carer involvement in the treatment and recovery of people who experience with a mental illness or emotional distress.
- Promote and advocate for authentic carer participation in the planning, delivery and evaluation of mental health services.
- Facilitate relationships between carers, carer workers, carer-focused organisations, groups and networks.
- Facilitate communication between carers, government and other stakeholders, advocating for positive policy change.
- Work in partnership with the Department of Health and other stakeholders.
- Promote the value of carer experience and carer co-design in service improvement and reform activities.
- Support and advocate for the diverse needs of mental health carers.
- Promote and support the development of the mental health carer workforce and leadership.

We also:

- Inform and empower mental health carers to access the National Disability Insurance Scheme (NDIS).
- Bring carer-based perspectives to mental health conferences and meetings, organising carer sessions and forums as appropriate.
- Develop and deliver training on family inclusive practice for mental health professionals.
- Provide information, education and training to members and others involved in caring for people experiencing mental illness or emotional distress.
- Administer the Carer Support Fund on behalf of Area Mental Health Services.
- Encourage and conduct research on best practice in carer support.
- Help raise community awareness about mental health issues and the important role of carers in the community.

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Overview

Tandem welcomes the opportunity to comment on the *National Disability Insurance Scheme Savings Fund Special Account Bill 2016*¹.

As the peak body for mental health carers in Victoria we support the '100 per cent' commitment of the government 'to deliver and fund the NDIS in full' and the commitment to ensuring that many areas of government are contributing to supporting people living with disability.²

We retain concern, however, regarding the implication of the 're-direction' of funds to the *Savings Fund*, as outlined in the *National Disability Insurance Scheme Savings Fund Special Account Bill* and re-affirmed in the Second reading by Social Services Minister Christian Porter³, for families and carers of a person living with a mental illness.

The 'principle of no disadvantage'⁴ is the commitment made by the government through the Intergovernmental Agreement for the NDIS Launch (IGA)⁵ that 'no one will be worse off' under the scheme, a promise that has been reaffirmed by Minister Porter. As outlined by the NDIA, where NDIS does not fund a support previously received by a participant, or if a prospective participant is not eligible for the NDIS, the Agency will identify alternative supports or refer the participant to other systems to ensure each person will achieve the 'same outcomes as a participant under the NDIS'.⁶

We recognise that not everyone with a mental illness will be deemed to have a level of impairment that results in psychosocial disability under the NDIS. Furthermore, whilst the NDIA recognises that carers and families are important partners in the support of people with psychosocial disability and acknowledge that carers and family provide help and support that cannot be provided by formal services or paid support workers, it remains unclear to what extent carers wellbeing and needs will be supported, in practice, under the NDIS.

With these points in mind, we recognise that many of the needs and supports required by mental health carers, and the person they care for living with a mental illness will be addressed by services beyond the scope of the NDIS.

As such, we wish to ensure the commitment of 'no disadvantage' is in no way undermined by the *National Disability Insurance Scheme Savings Fund Special Account Bill 2016*.

¹ *National Disability Insurance Scheme Savings Fund Special Account Bill 2016* (Cth)

² Commonwealth, Parliamentary Debates, House of Representatives, 31st August 2016 (Christian Porter)

³ Commonwealth, Parliamentary Debates, House of Representatives, 31st August 2016 (Christian Porter)

⁴ Australian Department of Human Services 2014, Fact Sheet – Principle of No Disadvantage
<<https://www.ndis.gov.au/document/what-principle-no-disadvantag.html>>

⁵ Council of Australian Governments 2013, Continuity of Support , Intergovernmental Agreement for the National Disability Insurance Scheme (NDIS) Launch < <https://www.coag.gov.au/node/485>>

⁶ Australian Department of Human Services 2014, Fact Sheet – Principle of No Disadvantage
<<https://www.ndis.gov.au/document/what-principle-no-disadvantag.html>>

The following submission outlines Tandems' concerns and recommendations regarding the *National Disability Insurance Scheme Savings Fund Special Account Bill 2016* to ensure that it:

- Allows for adequately and appropriately funded supports for the families and carers of a person living with a mental health issue, both within and beyond the scope of the NDIS
- Recognises the unique value of carers and families in supporting people living with a psychosocial disability
- Ensures that services beyond the scope of the NDIS remain adequately supported, resourced and funded.

Specifically, we are calling for greater explanation regarding the management of the re-direction of funds to the *Savings Fund*; and the implication, following the re-direction of funds, on families and carers, particularly those who will rely on supports that fall beyond the scope of the NDIS.

The submission will address the following concerns -

1. The possibility that the re-direction of existing disability related spending will negatively affect services supporting families and carers of a person living with a mental health issue outside of the NDIS
2. That savings have been, and may continue to be, re-directed to the *Savings Fund* at the expense of ensuring potential participants are fully informed of their rights under the NDIS.

We are hopeful that our reflections and recommendations on these points will go some way towards highlighting the particular concerns and needs of mental health carers.

Issues of Concern

Impact of re-directed funding on services supporting mental health carers beyond the scope of the NDIS

Due to a lack of articulation on how funding will be redirected from services, it is difficult to project how the re-direction of funds detailed in the *National Disability Insurance Scheme Savings Fund Special Account Bill 2016* may affect the services that support carers and families. Without greater clarity, we note our concern that a redirection of funds may result in a reduction in carer specific supports from what is currently offered.

1. Support for Carers of people eligible for the NDIS

Whilst the NDIS Act recognises that the *'role of families, carers and other significant persons in the lives of people with a disability is to be acknowledged and respected'*⁷, it remains uncertain how this will be reflected under the NDIS in practice and in what capacity NDIS recipients may include carer specific supports within their plan.

There remains a lack of detail on how the NDIS will support the wellbeing of carers and sustain their valuable caring role, making it difficult to project the extent carers and families will rely on services that fall beyond the scope of the NDIS.

2. Support for Carers of people ineligible for the NDIS

Secondly, the 'estimated percentage of the Australian adult population in need of NDIS individually funded supports as result of psychosocial disability related to mental illness, is expected to be 0.4 %: that is 12% of people with severe and persistent mental illness'⁸.

We recognise that many of the persons cared for by mental health carers will be ineligible for the NDIS, and will continue to rely on supports outside the scope of the NDIS, supports and services under the health and mental health system, or non-government organisations that receive State and Commonwealth funding.

Participants who require assistance with clinical and medical treatment, including diagnosis, for example, will continue to be funded by the health and mental health system⁹. It is important to recognise the financial burden families and carers already suffer in funding the medical and clinical

⁷ *National Disability Insurance Scheme Act 2013* (Cth) s4(12)

⁸ O'Halloran (2016) *Psychosocial Disability and the NDIS*, Introduction to the Concept of Holistic Psychosocial Disability Support Working Paper, quoting Productivity Commission 2011 *Inquiry into Disability Care and Support Report*, Report No. 54, Canberra. Appendix M p. M.4

⁹ See, Australian Department of Human Services 2014, Fact Sheet – 'Mainstream Interface: Mental Health Services' <<https://www.ndis.gov.au/people-disability/connecting-mainstream>>

services, such as out of pocket expenses and gap payments. If funds are redirected from supporting the health, mental health systems and non-government organisations that run the services outside of the NDIS we risk increasing the financial burden on families and carers to the detriment of sustaining the caring role, and therefore, the wellbeing of person they care for.

The NDIS Act states that ‘regard is to be had to the provision of services by other agencies, Departments and organisations and the need for interaction between the provision of mainstream services and the provision of supports under the National Disability Scheme’¹⁰. We seek assurance that the *National Disability Insurance Scheme Savings Fund Special Account Bill 2016* will not undermine this principle, and will not negatively impact services supporting those outside the NDIS.

Recommendations -

In light of the promise made that those who do not meet the requirements of the NDIS and are therefore ineligible for supports under the scheme will not be disadvantaged in the transition to the new arrangements and will be able to access the same level of supports they currently receive, *and* recognising that a core aim of the NDIS is to better support families in their caring role, and to ensure that role is nurtured and can be sustained; we state the following:

Recognising, that the NDIS is based on supporting people who have a permanent functional impairment as a result of their disability or a psychiatric condition; *and*

in acknowledgement, that it remains uncertain what supports will be provided to people living with mental health issues who are ineligible for the NDIS¹ (or who choose not to access the NDIS); *and, further,*

understanding, that carer specific supports are not directly recognised under the NDIS; *and*

due to, a lack of explanation about how the caring role will be sustained and considered in practice under the NDIS,

Tandem,

- stresses the importance of ensuring that robust, appropriate funding remains for services that respond to the needs of mental health carers and consumers;
- recommends that funds are not re-directed from existing services, for the purpose of contributing to the *Saving Fund*, to the detriment of these services and to the disadvantage of mental health carers and consumers who will continue to rely on those services that provide essential supports.

¹⁰ *National Disability Insurance Scheme Act 2013* (Cth) s3(3)(d)

Ensuring potential participants are fully informed of their rights under the NDIS.

Reflecting on the concerns and recommendations set out above, Tandem recognises there remains much uncertainty around what the NDIS will mean for consumers, carers and services.

It is with concern, therefore, that we observe that savings were made by the Government by abandoning a television advertising campaign ahead of the NDIS launch on July 1st, 2016.

Without adequate information participants will be unable to access information regarding their right to greater choice under the NDIS. This is particularly true of participants who are eligible due to a psychosocial disability and their families and carers, due to the complexity of their cases and experiences. Furthermore, in recognition of the culturally diverse population in Victoria, it is essential that CALD community members gain equal access to information in their language of choice.

As the peak body of mental health carers in Victoria we stress the importance of ensuring that all eligible participants are educated about the NDIS and are made aware of the services and funding they are entitled to under the scheme, and that this is undertaken through a variety of media sources so to reach the largest audience of prospective participants.

Reducing funding in this area, and failing to appropriately provide information, risks undermining the core objectives of the NDIS Act, including that it will;

- *Support the independence and social and economic participation of people with a disability*¹¹
- *Enable people with a disability to exercise choice and control in the pursuit of their goals and the planning and delivery of supports;*¹²

Recommendations –

Whilst we welcome that the *National Disability Insurance Scheme Savings Fund Special Account Bill 2016* will ensure that savings made within the NDIS will be retained as NDIS funding, we recommend it not be to the detriment of ensuring that mental health carers and consumers are aware of their rights and services available under the NDIS or undermining the core objectives of the NDIS.

¹¹ *National Disability Insurance Scheme Act 2013* (Cth) s1(c)

¹² *National Disability Insurance Scheme Act 2013* (Cth) s1(e)