

**Social Support & Precarious Workforce Research Discussion Group
at RMIT University**

Productivity Commission Issues Paper: National Disability Insurance

Scheme (NDIS) Costs

February 2017

Due Date Submissions: 24 March 2017

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We thank the Productivity Commission for the opportunity to make a submission to the National Disability Insurance Scheme Costs Issues Paper as we believe that it raises important issues for people with disability, their Carers, families and other supports.

The **Social Support & Precarious Workforce Research Discussion Group** is a group of **RMIT Academics, Early Career Researchers and Higher Degree Research students** who research workforce issues or disability services in the social support and care sector. We meet informally on a monthly basis with to share ideas, share our knowledge and exchange information on research areas of mutual interest. This submission was prepared by the following group members: Dr Raelene West, Dr Christina David, Elizabeth Hudson, Amaya Alvarez, Wendy Taylor. The views and opinions expressed in this article are those of the authors and do not necessarily reflect the views of RMIT university.

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This submission is in particular reference to section 4. **Planning Process Section.**

As noted in the NDIS Act 2013 and the Productivity Commission's discussion paper, participants approved to enter the NDIS scheme must undertake a planning assessment process in order to develop a plan that details their required living supports, service requirements and equipment, and that includes a statement of goals and aspirations. As detailed in the NDIS Act, the principles of the plans are listed as:

Part 2—Participants' plans

Division 1—Principles relating to plans

31 Principles relating to plans

The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

- (a) be individualised; and
- (b) be directed by the participant; and
- (c) where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and
- (d) where possible, strengthen and build capacity of families and carers to support participants who are children; and
- (da) if the participant and the participant's carers agree—strengthen and build the capacity of families and carers to support the participant in adult life; and

- (e) consider the availability to the participant of informal support and other support services generally available to any person in the community; and
- (f) support communities to respond to the individual goals and needs of participants; and
- (g) be underpinned by the right of the participant to exercise control over his or her own life; and
- (h) advance the inclusion and participation in the community of the participant with the aim of achieving his or her individual aspirations; and
- (i) maximise the choice and independence of the participant; and
- (j) facilitate tailored and flexible responses to the individual goals and needs of the participant; and
- (k) provide the context for the provision of disability services to the participant and, where appropriate, coordinate the delivery of disability services where there is more than one disability service provider.

A participant's plan must also include:

33 Matters that must be included in a participant's plan

- (1) A participant's plan must include a statement (the *participant's statement of goals and aspirations*) prepared by the participant that specifies:
 - (a) the goals, objectives and aspirations of the participant; and
 - (b) the environmental and personal context of the participant's living, including the participant's:
 - (i) living arrangements; and
 - (ii) informal community supports and other community supports; and
 - (iii) social and economic participation.
- (2) A participant's plan must include a statement (the *statement of participant supports*), prepared with the participant and approved by the CEO, that specifies:
 - (a) the general supports (if any) that will be provided to, or in relation to, the participant; and
 - (b) the reasonable and necessary supports (if any) that will be funded under the National Disability Insurance Scheme; and
 - (c) the date by which, or the circumstances in which, the Agency must review the plan under Division 4; and
 - (d) the management of the funding for supports under the plan (see also Division 3); and
 - (e) the management of other aspects of the plan.

Despite the listed principles of the plan process, we feel that the recently introduced 'phone-planning' under the My First Plan process is undermining the robustness and integrity of the principles of the NDIS Act in relation to the planning process. Further, we feel the introduction of the phone-planning has only been introduced as a shortcut and cost-cutting means of 'just getting participants onto the system', i.e. 'transitioning', and in doing so, undermines the comprehensiveness, thoroughness, and individual person centred nature principles of the planning process (see 31a, 31b above). We feel the phone-planning occurring under the My First Plan is a transactional and blunt approach at a critical stage of a participant's navigation and interaction with the scheme, and that phone-planning does not provide an adequate method in accurately determining a person's needs in the context of their family, social and community support systems, as should be the case (see 31c above).

The present strategy of utilising phone-planning in just rolling-over people who already have established state-based Individualised Support Packages (ISPs) into the scheme and as a way of simply moving participants into the NDIS, is in our view, simply a cost-cutting strategy, that does not allow for a proper and comprehensive review of participant support requirements in a manner consistent with the principles and objectives of the NDIS Act.

The planning process is the first interaction most participants have with the scheme and the development of planning into a cost-cutting and sub-standard effort is poor. The NDIS Act's principles detail a need for robust and thorough planning processes from the first point of entry into scheme, and phone-planning is unlikely to meet these principles for many people with disabilities or their family carers. We feel the intended planning process (as outlined in the Act) versus the actual planning process utilising phone-planning has as such, diverged too far from the principles of the Act and are not satisfactory to meet the needs of most NDIS participants.

In particular, we have heard of reported issues about who is in the room and who should be in the room during the phone-planning process, and that there is lack-of-understanding by participants around privacy with support workers and others being present, and conversely that those needing others to be present that would be to their benefit (informal carers and such) are not actually present at the time of the phone-planning. Further there are challenges with the extent to which a nominee is speaking for a participant and if supported decision-making is being enacted, and the extent to which this can be monitored and observed in utilising phone-planning. The potential for others to speak-for and make-decisions-about a participant who is non-verbal or has an intellectual disability is thus heightened with phone-planning. Other reports have suggested a lack of understanding by participants of what phone-planning is, and that some participants are not fully aware that the phone conversation occurring with the NDIS staff member is actually their planning process occurring. This confusion is also evident in the NDIS marketing of phone-planning as a 'planning conversation', where the suggestion is you will 'talk-about' the plan whereas the reality is that it is a full and structured assessment and plan procedure.

Further, given the newness of the planning process, participants may not be aware that they can request a face-to face planning meeting if they wish, particularly given the normalising marketing strategies of phone-planning by the NDIS. The newness of the planning parameters means participants themselves may not realise the inadequacies of the phone-planning system and the inequity between their phone-planning experience and that of another participant engaging in a face-to-face planning meeting with a planner. The reduced quality of outcomes and equality for participants could be severe, and awareness of these inequities contributes to reduced overall confidence in the scheme.

We feel utilization of phone-planning also creates assumptions of living situation by planners, who are unable to adequately capture the requirements and considerations of participants and respect the role of family, carers and other persons who are significant in the life of the participant. Phone-planning is unable to convey to the planner what the sense of community, social and family is, and in what contexts these interactions and inclusions/exclusions are occurring in. Further, the phone-planning model is not based-on or supported by any research literature, nor has the policy/strategy been piloted or evaluated. In this sense, phone-planning seems to have just been implemented by the NDIA without being tested or assessed with just an assumption model is ok.

Our discussion group likened the analogy of phone-planning to having a GP assessment by phone, where the condition is not really observed by the GP but instead the patient makes a self-assessment of the condition in language they know and/or can communicate to the GP over the phone, and the GP makes their diagnosis of a treatment plan based on that account. We feel the phone-planning is inherently unfair and inadequate to create tailored and flexible planning outcomes. We question how planners are able to maximise choice and independence of a participant, and emphasise the difficulties for planners in being able to really determine what is reasonable and necessary, and in obtaining context of details required for a plan.

NDIS literature:

NDIA video link: <https://www.ndis.gov.au/participants/firstplan>

From NDIS website:

My first plan

Your first plan is the start of a lifelong relationship with the NDIS.

Once you have gained access to the NDIS we will work with you to develop your first plan.

Your first plan is your entry point to the NDIS and the start of your relationship with the Scheme.

Your first plan will identify the reasonable and necessary supports you require to meet your immediate needs and start to identify and achieve your goals.

Once completed – your first plan will provide you with individualised funding that you control and choose how to use.

To get ready for the NDIS and your first plan, start thinking about your immediate support needs and what your current and future goals might be.

Below are video links of a current NDIS participant talking about their first plan:

<https://ndis.gov.au/medias/documents/h68/h80/8798779670558/Checklist-Getting-ready-for-your-planning-conversation-21.10.16-accessible.pdf>

<https://ndis.gov.au/medias/documents/hee/ha0/8798779113502/Fact-Sheet-Developing-your-NDIS-plan-21.10.16-accessible.pdf>

From NDIS website:

How do I get my first plan?

Once your access to the NDIS is confirmed, you and/or your nominee will be contacted by a representative of the National Disability Insurance Agency (NDIA) to have a planning conversation. Most people's first plans will be completed over the phone, through a planning conversation between the participant (and/or their nominee) and an NDIA representative about their existing supports, needs and main goals.

If you are not able to complete your planning conversation over the phone or are not in a position to do so, the NDIS will make alternative planning arrangements. Everyone will have the same access to supports and services irrespective of how their planning conversation takes place. Once in the NDIS, your plan will be reviewed every 12 months, including your first plan.

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As noted above, we feel the introduction of phone calls in the planning process has departed from the principles of the original planning process of the NDIA Act. In the original planning process outlined, plans would be developed by the NDIA planners (Ref: NDIS 2016). Since then, the planning process within the scheme has gone from a NDIA planner doing all plans, to less trained LACs being out-sourced to doing plans, to call 'phone planning'. Our understanding is that NDIA planners were meant to develop plans with clients with complex needs (20% of clients) and LACs were to develop plans for the other 80% of participants. No data has been released on the percentages of planning now occurring under the phone-planning model or comparative evaluations of the model.

Identified concerns with developing plans over the phone are:

- The participant doesn't know what is being written down and cannot review summary
- It may be difficult for some people to communicate issues and needs over the phone and articulate issues correctly, particularly if planner/LAC has no visual on living environment, equipment,
- It's difficult to assess if participants are participating to their fullest extent possible
- the planer only obtains an interpretation of situation as participants sees it; potential for creating bias of situation , certainly choice and control by participant, but thorough planning needed to get good outcomes

- Role of nominee - speaking for participant; how do you observe if participant is consulted/that supported decision making is occurring with phone planning

In completing a quality, thorough and robust plan, planners need to be on site to assess in real time:

- observation of body language and pick up on non-verbal cues
- observation of a person's ability to self-care; their mood; their living situation and environment; relationship with carers/families; and whether this is at risk of breaking down
- observation as to if the appointed nominee is supporting the participant adequately in supporting decision-making (and not just any family member or the rostered on support worker)
- observation of the extent to which a participant is able to participate in the planning process
- whether the participant/family member is able to understand the content of the plan and what a plan looks like
- in order to assess accurately information in the context of the living environment of the participant
- How do planners observe informal support networks are adequate/appropriate - that coercion isn't present

In attending a planning meeting on-site, there is more likelihood of

- Reaching agreement on a plan is more likely
- Understanding about plan and planning process is more transparent, clear
- Face to face are likely to be more collaborative

It is evident, the introduction of phone-planning creates structural issues for the scheme. Although upfront costs are saved in not having to have a NDIA Planner or LAC attend in person, costs saved are at the price of a thorough planning review. This will impact on long term *delivery of* the scheme, potentially requiring more frequent adjustments because of dissatisfaction with plans (NDIA 2016g). Phone-planning achieves an efficiency within the scheme at the cost of quality planning.

As a case-study on capacity for planning by participants, one participant placed an ad in Air Tasker wanting support for their up-coming phone-planning. We feel this is highly problematic, and that it is the role of NDIA planning to be costing the need for a thorough planning process, not having individuals take on personal cost in order to participate in a robust and comprehensive planning process:

ad <https://www.airtasker.com/tasks/assistance-with-ndis-form-3482454/>

- Why are participants feeling the need to pay people to assist them with plans?

Certainly phone-planning and assessment impacts on the quantum and quality of supports participants receive.

Participants with mental health issues

Active lobbying by the disability sector precipitated the Australian Government to undertake an inquiry (2010) into the development of the NDIS. It was only after some deliberation that those with psychosocial disability were included in the scheme (Productivity Commission, 2012). As the NDIS has been essentially shaped by the disability sector and mental illness as an afterthought in its conception, a number of concerns have been raised by the sector including whether the scheme is adequately resourced to meet the needs of those with fluctuating needs (Williams and Smith 2014)¹. Our discussion group shares these concerns.

There are particular needs of clients with mental health issues. There may need more than one meeting to develop plans due to fluctuating nature of conditions, e.g. some days thinking of goals would be unachievable.

A further issue for participants with mental health issues could be where phone-planning could be organised on a day where a participant has low energy levels or is not motivated on that particular day - if because of this, the needs are not then correctly articulated, then participants may miss out on crucially needed supports due to the impact of this on their assessment. A face-to-face planning meeting would allow planners/LACs to more accurately assess the overall health, lifestyle and living conditions of a participant in a more holistic way rather than on how a participant 'was feeling on the day' and give participants the ability to contribute to planning process at a more comprehensive level.

Participants with literacy and/or language barriers

People not proficient in English or who have literacy and comprehension issues will struggle with phone-planning. This group of participants may include newly arrived migrants and/or people with low literacy and comprehension due to their particular impairments. The lack of visual cues and the opportunity to clarify questions face-to-face will produce particular problems for these groups. Further, it cannot be assumed that people in these groups will identify that they have a literacy or comprehension issue, particularly given their desire to join the NDIS and begin the process. There is also the risk that they may not understand what the conversation is about and are simply complying with authority due to cultural or social norms. This means that their initial plan could be highly superficial, providing only basic supports and not addressing more pressing needs. People may enter the NDIS without understanding their rights and responsibilities in the scheme, thus setting the scene for problems and issues in the future.

It is also difficult to see how such phone-planning processes equate with a vision of people optimizing community supports and engaging more actively with the community.

Planner training

Sufficiently skilled and impartial planners/LACs are important for the ongoing financial sustainability of the scheme, and it would appear that not enough LACs have been employed or trained in the role and hence the move to phone-planning was adopted and rapidly normalized. We question:

- Why participants are doing queasy phone assessments with untrained LACs when a qualified planner should be conducting assessments face-to-face?
- Is there a base level for planners – How is this measured?

¹ Williams, T. & Smith, G. 2014. Can the National Disability Insurance Scheme work for mental health? Australian and New Zealand Journal of Psychiatry, 48, 391-394.

- Is there are handbook/guidelines on different disabilities so all planners have a similar info on developing plans for people with different types of conditions? And how realistically can any training produce adequate results when all of this knowledge is compressed into a phone assessment?
- If participants themselves should be given opportunity to assess planners/LAC performance?
- If there is a need for info on the quality of the plans, not just the numbers being produced
- Is there potential to compare plans for collective of different groups? E.g. participants with spinal injuries?

This all comes in light of reports on ABCnews from freedom-of-information documents obtained, that noted that most LACs had not received adequate training:

<http://www.abc.net.au/news/2017-03-12/ndis-rollout-plagued-with-problems-foi-documents-reveal/8346892>

Less than one third of organisations trained by deadline

Training for local area coordinators (LACs) was also marked "code red" on the committee's pre-launch tracking system.

Nearly 550 coordinators were supposed to be trained by late-June. But only about 150 had done an online program and just 54 had received face-to-face training. LACs are private organisations contracted to act as a conduit between people with disabilities, the agency and service providers.

Increase NDIS Planners' understanding of psychosocial disability and the mental health recovery framework

Permanence of impairment and a mandate for life time support are terms embedded in NDIS legislation as preconditions for determining eligibility². As a consequence, those who do not identify as having a disability or cannot reconcile compatibility between permanence and the recovery model, are less likely to attract funding under the NDIS.

"Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"³

Mental health experts⁴ and consumer and carer groups⁵ report it is challenging to reconcile the language of permanent impairment with a recovery framework, because it limits opportunities of

² Federal Register of Legislation, *National Disability Insurance Scheme (Becoming a Participant) Amendment Rules 2016 (No. 2)*, Australian Government, 2016.

³ M Slade and E Longden, 'Empirical evidence about recovery and mental health', *BMC Psychiatry*, 15:285, 2015, pg. 527.

⁴ Mental Health Council of Australia, *Mental Health and the National Disability Insurance Scheme Position Paper*, 2013;

B Bonyhady, 'Tides of change: the NDIS and its journey to transform disability support', *Newparadigm: the Australian Journal on Psychosocial Rehabilitation*, Summer 2014, 7-9; T M Williams, and G P Smith, 'Can the

hope and optimism for people with mental health issues. A recovery framework is widely accepted as mental health best practice,⁶ and we acknowledge that the NDIA demonstrates a willingness to broaden the understanding of recovery framework across the NDIS network. However, more could be done to embed a shared understanding of recovery in practice in the NDIS.

Formal, evidence based training for NDIS staff and partners designed in consultation with people with lived experience would aid in building an empathic understanding of the significance of language in recovery. It would also assist in demonstrating how NDIS tenets of choice and control and social inclusion facilitate recovery. As recommended by Mental Health Australia,⁷ the NDIA could also consider developing a suite of operational tools and guidelines, which reflect the recovery framework to help implement the scheme effectively with participants with psychosocial disability. These could be developed to augment existing NDIS information offerings such as recovery fact sheets.⁸

Disability assessment for people with mental illness poses a more significant challenge than for other disability groups. This is due to the complexities associated with separating symptoms from impairment.⁹ As episodes of disability or illness are not always immediately obvious, some people with episodic disability may appear 'well' to an outsider or over the phone, invoking doubt and suspicion about the severity of their disability, and this may disadvantage them during eligibility assessments.

A deeper understanding of the impact of language and the 'hidden' nature of psychosocial disability across the NDIS network would assist in improving access for people with psychosocial disability. Furthermore, as outlined at the National Mental Health Consumer and Carer forum¹⁰, assessments undertaken for people with psychosocial disability could be better administered by people trained in the use of appropriate assessment instruments and by those who have knowledge of psychosocial disability issues including support requirements and available support resources. These assessments would most certainly be ineffective within a phone-planning model.

Copy of Plan

Further, in relation to the Act and clause:

38 Copy of plan to be provided

The CEO must provide a copy of a participant's plan to the participant within 7 days after the plan comes into effect. We feel participants should be provided with a draft copy of their plan before it comes into effect so that it can be satisfactorily reviewed before being finalized.

In terms of providing pre-planning support for participants with psycho-social conditions:

National Disability Insurance Scheme work for mental health?', *Australian and New Zealand Journal of Psychiatry*, 2014, 48(5): 391-394; M Slade and E Longden, 'The empirical evidence about mental health and recovery: how likely, how long, what helps', *Melbourne: MI Fellowship*, 2015.

⁵ Victorian Mental Illness Awareness Council (VMIAC) and Tandem (Victorian peak body representing families and carers of people living with mental health challenges)

⁶ A T Edgley, T Stickle, N Wright and J Repper, 'The politics of recovery in mental health: A left libertarian policy analysis', *Social Theory & Health*, 2012, 10(2): 121-140; A Nicholas and L Reifels, *Mental Health and the NDIS: A Literature Review*, 2014.

⁷ Mental Health Australia, *The implementation and operation of the psychiatric disability elements of the National Disability Insurance Scheme: A recommended set of approaches*, Technical paper prepared by David McGrath Consulting on behalf of Mental Health Australia, p.33.

⁸ NDIS, *Psychosocial disability, recovery*,

<https://www.ndis.gov.au/medias/documents/heb/h21/8799160959006/Fact-Sheet-Psychosocial-disability-recovery-and-the-NDIS-PDF-774KB-.pdf>, accessed Feb 2017

⁹ J C Wakefield, 'Disability and diagnosis: should role impairment be eliminated from DSM/ICD diagnostic criteria?' *World Psychiatry*, 2009, 8, 87-88

¹⁰ National Mental Health Consumer and Carer Forum, 2011

We endorse the recommendations made by Victorian Council of Social Services (VCOSS) members regarding pre-planning support: “people with psychosocial disability may face difficulties navigating and understanding the NDIS, be reluctant to engage with the NDIS or service system because of stigma surrounding mental illness, be unaware they are unwell or not identify with having a disability, or find the process intimidating or lack motivation to go through the application process. Therefore, it is recommended that pre-assessment support is provided to help people understand the NDIS, check their eligibility, help prepare for the planning session so the plan meets their needs and provide assistance in lodging their application, if required”.¹¹

Funding pre-assessment support and pre-planning support for people who require greater assistance could help achieve better outcomes for participants and improve engagement. Lessons can be learnt from the Australian Capital Territory, where grants¹² of up to \$1,000 were available to individuals to engage a planner to assist with pre-NDIS preparation and support and the funded pre-engagement support in the Barwon launch site. Proactive outreach from planners along with access to independent advocates to help negotiate support would further help engage people with psychosocial disability.

¹¹ VCOSS submission to the Joint Standing Committee Inquiry on the NDIS : *Delivering high quality services to all mental health consumers*, February, 2017, p.10

¹² ACT Community Services, Grants,

http://www.communityservices.act.gov.au/disability_act/national_disability_insurance_scheme/grants

Recommendations:

As such, we are highly concerned about the emergence of phone-planning such as is being rolled out under My First Plan for NDIS planning processes. We provide the following recommendations:

- Phone-planning to be utilised in none but rare or extenuating situations (or at a participants specific request)
- Participants should expect face-to-face planning meetings and the distinct benefits it offers
- allow sufficient time for participants to organise people for face-to-face planning meeting
- phone-planning not used as an cost-efficiency measure at expense of quality
- provide participants draft copy of plan for review before finalisation
- introduce self-assessments of planning by participants
- increase LAC training to reduce variation within planning process
- Increase training of LACs to deal with diverse knowledge required with assessments during planning
- Provide improved pre-planning support