Australian Red Cross
THE POWER OF HUMANITY

Submission regarding the Productivity Commission Inquiry into National Disability Insurance Scheme costs

July 2017

Australian Red Cross is committed to making sure that the National Disability Insurance Scheme (NDIS) enables all Australians, particularly the most vulnerable, to access the help, supports and services they need.

This commitment is in line with our strategic direction to improve the wellbeing of those experiencing extreme vulnerability, including working towards the outcome that 500,000 Australians are connected to and supported by the community to overcome their deep social exclusion.

The introduction of the NDIS is a once in a generational change to human service delivery in Australia and Red Cross welcomes the opportunity to work collaboratively in order to ensure that those experiencing vulnerability are able to harness the full benefits of the scheme in order to participate in the social and economic life of our community.

I would welcome the opportunity to discuss our submission further.

Judy Slatyer

Chief Executive Officer

Summary of Recommendations

We recommend:

1. The NDIA develops targeted mechanisms to ensure that vulnerable people, particularly those most at risk of deep social exclusion, are supported to access and engage with the scheme and that these mechanisms are co-designed with participants.

2. The NDIA provides a mechanism to accurately and consistently assess scheme eligibility (prior to full scheme rollout) for people experiencing psychosocial disability.

3. Pending more rigorous estimates of scheme eligibility for people experiencing psychosocial disability, that Commonwealth, State and Territory Governments develop with relevant stakeholders, appropriate support arrangements for people experiencing psychosocial disability to ensure that they are not disadvantaged by the implementation of the NDIS.

4. The options detailed by Mental Health Australia[i] on recovery oriented psychosocial support be considered for adoption to provide clearer definitions of NDIS eligibility criteria for people with psychosocial disability.

5. The NDIA ensures that all initial assessments and planning with participants and their families are conducted face-to-face with adequate notice for people to prepare, including arranging supporters or advocates to be present as necessary.

6. The NDIA ensures that planning teams have relevant skills and expertise including in psychosocial disability and co-morbidity factors, in order to better support the crucial initial planning session with participants.

7. The NDIA works with State and Territory Governments to ensure that continuity of support arrangements are in place and clearly communicated with stakeholders in order avoid unintended consequences from the withdrawal of state/territory funded services, in particular, community based mental health services.

8. The NDIA, the Commonwealth and State and Territory Governments ensure that funding is guaranteed for community-based supports for people living with psychosocial disability.

9. The interfaces between the NDIS and justice systems are urgently examined to implement an effective and integrated throughcare approach.

10. The NDIA co-designs mechanisms for addressing thin markets with participants and other key stakeholders.

11. The NDIA engages with service providers (not limited to disability service providers) and participants to explore and potentially co-design approaches to support vulnerable people to access and engage with the scheme.

How is the scheme tracking?

We share the view of the Productivity Commission in draft finding 2.4 that people with a psychosocial disability and those who struggle to navigate the scheme are at risk of experiencing poor outcomes. In addition, we also highlight that there are a number of other system issues and high risk groups that should be considered in the context of who is at risk of poorer outcomes as a result of the implementation of the NDIS.

In line with these concerns, Australian Red Cross commissioned the University of Adelaide's Centre for Urban Housing, Urban and Regional Planning to review the literature in Australia and internationally about groups at risk of disadvantage through the introduction of user choice systems across both the NDIS and aged care sector[ii]. The key findings include:

- There is a lack of concrete evidence about unmet need and therefore it is difficult to identify with any certainty specific locations where 'thin markets' either currently exist or may exist in the future.
- It is likely that there are groups and individuals yet to be identified who are marginalised, will be further marginalised, and/or who are experiencing deep social exclusion and who will be disadvantaged by the transition to self-directed care.
- Those groups and individuals identified in the report as being most likely to be adversely impacted by the reforms strongly correlate with the groups identified by Red Cross as at risk of experiencing deep social exclusion.
- Many disadvantaged individuals are disadvantaged across multiple domains, including those with poor system literacy.
- Despite the recognised importance of advocacy in enabling people to build skills and capacity within a self-directed care model, future funding for independent advocacy support is uncertain.
- Without targeted services, people with mental ill-health will continue to 'fall through the gaps'.
- There is little evidence nationally and internationally reporting positive outcomes under personalised care funding arrangements, including outcomes for vulnerable groups and people living in diverse locations.

Based on this as well as other evidence presented in the commissioned report and our community-based experience, we have significant concerns not only for people who experience psychosocial disability, but also for others who are vulnerable to these changes including:

- People who are financially and socially disadvantaged
- People with specific cultural needs including (Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse backgrounds, lesbian, gay, bisexual, trans, intersex, queer people)
- People with limited or poor system literacy
- People with impaired mental capacity
- Carers

- People in regional and remote areas
- People who are caught between the aged care and disability service systems
- Veterans
- People who have been, are, or are at risk of homelessness
- Care leavers
- Women with a disability
- Young people in residential care
- People resistant to receiving social support
- People involved in the justice system

There may also be others not yet identified, who will not engage with the scheme and be disadvantaged.

We recommend:

The NDIA develops targeted mechanisms to ensure that vulnerable people, particularly those most at risk of deep social exclusion, are supported to access and engage with the scheme and that these mechanisms are co-designed with participants.

Scheme eligibility

Red Cross agrees with draft recommendation 3.1 from the Productivity Commission about collecting data on activity domains to help monitor and track patterns in scheme eligibility. We have a particular concern about the eligibility of people who experience psychosocial disability.

We note that the Productivity Commission's position paper reports that 81% of people with a psychosocial disability who lodged an access request to the NDIS were eligible for the scheme. This figure is at odds with our experience in supporting clients in the Personal Helpers and Mentors (PHaMs) program. Estimates based on medical diagnosis, receipt of a Disability Support Pension, 'severity and persistence' of client mental health condition (including episodic frequency) and associated level of 'functionality and likelihood of lifelong' effect have indicated that 70% of our current PHaMs clients are likely to be ineligible for an individual funding package. We have significant concerns about the ability for these people to access appropriate supports under full scheme rollout when PHaMs is withdrawn.

We note that the Commission does not support changing the eligibility criteria to ease the definition of permanency and how it relates to psychosocial disability. Mental Health Australia, in their supplementary submission to the recent Joint Standing Committee on the NDIS, proposed a range of options specifically designed to help people with the greatest need access support, rather than to 'relax' the criteria[iii]. We support serious consideration of these options, which focus upon achieving recovery oriented psychosocial support in the NDIS and specific legislation changes in relation to terminology, regulation and operational processes.

Regardless of eligibility criteria, we are also concerned that some people who are already experiencing vulnerability may be unwilling to seek access to the NDIS, irrespective of their potential eligibility for support. Red Cross clients have reported that their reluctance to engage with an additional support system is borne out of long and often adverse experiences with government service systems. This was emphasised to us by clients living in regional communities who told us "*it's just too hard … all the paperwork and that …I don't have the energy. I'm just surviving day to day"* and *"NDIS - I got enough problems. I don't need to worry about that shit".*

We recommend:

The NDIA provides a mechanism to accurately and consistently assess scheme eligibility (prior to full scheme rollout) for people experiencing psychosocial disability.

Pending more rigorous estimates of scheme eligibility for people experiencing psychosocial disability, that Commonwealth, State and Territory governments develop with relevant stakeholders, appropriate support arrangements for people experiencing psychosocial disability to ensure that they are not disadvantaged by the implementation of the NDIS.

The options detailed by Mental Health Australia[iv] on recovery oriented psychosocial support be considered for adoption to provide clearer definitions of NDIS eligibility criteria for people with psychosocial disability.

Scheme supports

For many people, particularly vulnerable people who may face barriers in engaging with government service systems, the development of their first NDIS plan is a critical point that will not only ensure that they are able to access the supports they need, but will also shape their first impressions and willingness to engage with the NDIS.

We echo the concerns noted by the Commission on the planning process, including significant concerns around the appropriateness of phone planning particularly for vulnerable people. It is critical that the initial phase of engaging with participants who are seeking to access NDIS is face-to-face with the participant and their carers. Where this has occurred with no pre-planning for the participants and/or via phone, the results are unlikely to lead to a plan which will meet the participants need. We further endorse the Commission's recommendation that Local Area Coordinators are in place six months prior to scheme rollout to ensure that appropriate pre-planning activities are undertaken to prepare participants and providers.

Our commissioned research, as well as feedback from our clients has detailed how issues of trust and communication impact on the effectiveness of the planning processes, with clients stating "*I'm quite shy to get to know people at first*", "*You've got to have a trust and a bond*" (with the mental health worker) and "*the confidentiality is massive*".

Others talked about the lack of support to access information and services, "*No one around me. I was just on my own. I found it hard to communicate with people*".

We also have concerns around scheme entry for people who face multiple co-morbidities and that the NDIA ensures there are specialised and joined up approaches for scheme entry that take into account the complexity of co-morbidities and use community-based supports.

Clients have repeatedly reported that they faced barriers to accessing appropriate services when they had both mental health and substance use issues, with mental health services refusing support because of their substance use, and vice versa.

We recommend:

The NDIA ensures that all initial assessments and planning with participants and their families are conducted face-to-face with adequate notice for people to prepare, including arranging supporters or advocates to be present as necessary.

The NDIA ensures that planning teams have relevant skills and expertise including in psychosocial disability and co-morbidity factors, in order to better support the crucial initial planning session with participants.

Boundaries and interfaces with the NDIS

We support recommendation 5.1 as detailed in the Commission's position paper regarding the full funding of Information, Linkages and Capacity Building (ILC) during scheme rollout. We believe that adequately funded ILC functions are critical for groups such as:

- People with non-permanent or episodic disability
- People who formerly received state/territory disability support
- People in need of advocacy support
- People with a disability with other complex support needs delivered by mainstream sectors such as health, mental health, housing
- People with a disability needing referrals to mainstream supports generally.

We agree with draft recommendation 5.2 from the position paper that state and territory governments clarify their approach to continuity of service arrangements. The present uncertainty is adding burden for participants and their families/carers who are already managing many challenges in their lives. We are concerned that without continuing community-based supports for people with mental ill-health, a significant additional burden is likely to fall on families, communities, acute mental health, welfare and justice services, resulting in considerable social and economic costs.

With regard to the Commission's recommendation 5.3, on the interface with mainstream services, we are concerned about the gaps and barriers created by the boundaries with the justice system. Given the high rate of people in prison with a disability[v], the high costs of imprisonment (compared with the cost of an NDIS package) and the lack of integration between the justice and disability

systems, this situation warrants urgent attention. The submission from the Public Health Association of Australia to this inquiry provides a clear, comprehensive and compelling rationale for this recommendation[vi]. Case management throughcare models are crucial for reducing inequity and improving the health, social and justice outcomes for people with a cognitive disability in the criminal justice system[viiviii].

We recommend:

The NDIA works with State and Territory Governments to ensure that continuity of support arrangements are in place and clearly communicated with stakeholders in order avoid unintended consequences from the withdrawal of state/territory funded services, in particular, community based mental health services.

The NDIA, the Commonwealth and State and Territory Governments ensure that funding is guaranteed for community-based supports for people living with psycho-social disability.

The interfaces between the NDIS and justice systems are urgently examined to implement an effective and integrated throughcare approach.

Provider readiness

We strongly believe that people should be able to access the help they need, regardless of location. We share the Commission's concerns about thin markets and the resulting lack of choice and control for people who need to access support within this environment.

Our commissioned research also demonstrated that there is a lack of data on precisely where thin markets may occur and what their characteristics might be. We believe that in order to arrive at viable solutions it is necessary to fully understand the scale and complexity of the issue and would welcome further research into this area.

The report on sustainable and remote workforce for disability from the Centre for Applied Disability Research[ix] offers some suggestions of how thin markets may be addressed, such as paying family members as carers in exceptional circumstances.

Technology is often proposed as a potential solution to the lack of clinical health experts to provide diagnostic and clinical supports in rural and remote locations (thin markets). However, our clients living in rural and remote communities have questioned the assumption that technology alone will provide a viable alternative to face-to-face services. The key issues raised by our clients include:

- The difficulty of creating rapport and trust with the clinician or service provider via phone, video-conference or email, which clients viewed as impersonal
- The lack of reliable broadband access or access to smartphones or computers (particularly in remote communities)

- The discomfort of responding to personal and at times, re-traumatising questions to a person with whom the client has no existing relationship, especially when the client then has to walk away after the 'appointment' with no local follow up or support *"it's people's lives that you are stuffing with"*
- The inconsistency of clinical and support staff, with clients reporting that they had to re-tell their story to a new person multiple times because staff are allocated based on availability rather than on the basis of an existing relationship with the client.

We recommend:

The NDIA co-designs mechanisms for addressing thin markets with participants and other key stakeholders.

Participant Readiness

We agree with the Commission's comments regarding the diversity of NDIS participants and their varying levels of capacity to navigate the scheme and acknowledge that given the scale of the reforms a degree of 'learning by doing' is inevitable.

However, we have real concerns that vulnerable or isolated people may be excluded from the benefits of the reform.

With regards to information request 8.2 from the position paper, we encourage further analysis and consultation on this issue, noting anecdotal evidence indicates that in many locations Local Area Coordinators have been overwhelmed by demand for plans and so may not have adequate capacity to engage with and support very vulnerable and hard to reach groups. We encourage further analysis and exploration of the role of support coordinators and local disability support organisations.

With regards to draft recommendation 8.1 from the position paper, we note that given concerns about system literacy being a barrier to engagement with the scheme, mechanisms such as the eMarketplace may not be effective in supporting access to the scheme for people who are extremely marginalised.

We recommend:

The NDIA engages with service providers (not limited to disability service providers) and participants to explore and potentially co-design approaches to support vulnerable people to access and engage with the scheme.

References

[i] Mental Health Australia, 2017. *Options for achieving recovery oriented psychosocial support in the NDIS.* Accessed June 29 2017 https://mhaustralia.org/sites/default/files/images/supplementary_submission_re_options_for_achieving_recovery_oriented_psychosocial_support_in_the_ndis_18_may_mha_mifa_cmha.pdf

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[v] Dias S, Ware RS, Kinner SA, Lennox NG. Co-occuring mental disorder and intellectual disability in a large sample of Australian prisoners. *Australian and New Zealand Journal of Psychiatry*. 2013; 47 (10) 938-944.

[vi] Public Health Association of Australia 2017. *Submission on the National Disability Insurance Scheme Costs Issues Paper*. Accessed 24 June 2017 from http://www.pc.gov.au/__data/assets/pdf_file/0004/215770/sub0134-ndis-costs.pdf

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[viii] Abbott P, Magin P, Lugic S, Hu W. Supporting continuity of care between prison and the community for women in prison: a medical record review. *Australian Health Review* 2016.

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