Submission regarding the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

February 2017

Australian Red Cross welcomes the opportunity to provide a submission regarding the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition. We encourage further consideration of the intersection between NDIS, mental health reform and aged care reform to ensure that people experiencing mental ill-health are not being disadvantaged and are able to meaningful participate in and contribute to Australian society.

We support the reforms and policy positions seeking to address inequality and create an inclusive society with full social and economic participation by all people. We believe that mental ill-health is a major health and social policy issue, requiring a whole of government and community response with regional planning and delivery to better address needs across all locations.

Our experience working with the most vulnerable people in communities indicates that early intervention and prevention programs and community-based supports, in particular psychosocial supports, are pivotal and must be supported as part of the NDIS implementation. We are concerned that the NDIS and other reforms pose serious risks of people experiencing mental ill-health falling through the gaps of service provision.

We are committed to developing sustainable outcomes and joined up service solutions by partnering with government, business, philanthropists and people with lived experience of mental ill-health to address such potential risks.

Our submission includes recommendations regarding six of the nine criteria outlined in the terms of reference. Our focus is on the most vulnerable groups of people affected by mental illness in the community, many of whom are clients in our services across the country, who may be left behind as these key reforms are implemented.

As with our recent submission to the 5th National Mental Health Plan, we have provided information regarding the actions we are taking to address the emerging service gaps in the mental health sector through our investment in co-design activities in order to co-create joined up service solutions in the mental health sector.

The social and economic benefits of improved mental wellbeing are profound and worth striving for. We believe that this Joint Committee of Inquiry offers a crucial opportunity for people living with psychosocial disabilities.

I would welcome the opportunity to discuss this submission further.

Judy Slatyer

Chief Executive Officer

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Summary of Recommendations

Red Cross recommends that:

1. The NDIA provides a clear definition of the NDIS eligibility criteria for people with psychosocial disability to stakeholders, with a review of the criteria to be conducted as new information emerges around unmet needs for people with psychosocial disability.

2. DSS conduct a review into the eligibility rates for NDIS applicants with a primary mental illness to investigate the high rejection rate of applications for this client group in comparison with applications from people with physical, intellectual and/or sensory disabilities.

3. DSS adopt a co-design approach for the provision of services under the NDIS for people with psychosocial disability related to a mental health condition to ensure they are fit for purpose.

4. DSS maintain the Personal and Helpers and Mentors Support (PHaMS) program alongside the NDIS to provide services for people who are not eligible for the NDIS, until the full implications of the transition of mental health funding are addressed.

5. DSS consider the need for ongoing funding arrangements, including block funding, for services to meet the needs of vulnerable people who are unable to access providers due to cultural sensitivities, lack of family support to navigate the system, those in regional and remote locations or those who are unable to access appropriate diagnosis.

6. DSS invest in further research to identify, understand and address new service gaps as they emerge over the full implementation of the NDIS.

7. Governments work with service providers and others to improve understanding about the mental health system among vulnerable groups to ensure that they are able to access supports and services.

8. State and territory governments should work with the Australian Government to ensure that there are no unintended consequences from their withdrawal from mental health services.

9. NDIS strengthen its communications to stakeholders including service providers, potential clients living with mental ill-health and others to ensure that they are able to access appropriate services in a timely way.

10. DSS should provide targeted funding under the Information, Linkages and Capacity Building stream (ILC) within the NDIS for community based mental health services to support the needs of people living with psychosocial disability.

11. Primary Health Networks (PHNs) should support implementation of the NDIS in the following ways:

(i) seek opportunities to be involved in co-design activities within their local area

(ii) build their capability in evidence based mental health and co-design to ensure people with mental illness, specifically psychosocial disability and their families are part of the decision making regarding service design and response within each network.

(iii) ensure that Aboriginal controlled organisations are supported to continue providing culturally appropriate mental health services.

12. Ongoing NDIA planning should address the particular needs of and service gaps of those in outer metropolitan, regional and remote Australia, including Aboriginal and Torres Strait Islander peoples.

13. Access to peer workers should be included as a component of outreach services and community based mental health services.

1. ***That the joint committee inquire into and report on the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition, with particular reference to:***
    a. ***the eligibility criteria for the NDIS for people with a psychosocial disability***

The National Disability Insurance Scheme (NDIS) was not initially designed for psychosocial disability and as a result, clarification about the eligibility criteria for NDIS individualised funding for people with a psychosocial disability has been unclear and contestable for some time. We are becoming increasingly concerned about the likelihood of people experiencing mental ill-health falling through the gaps in these ambitious and wide-ranging reforms. As the NDIS focuses on “people with severe and permanent disability”, it is reasonable to expect that many people with mental ill-health will be ineligible to receive individualised funding. For example, people with short or medium term but severe conditions (such as Post Traumatic Stress Disorder or some forms of depression), those with highly episodic conditions (such as bipolar disorder) and those who do not have a diagnosis but whose lives are severely impacted by mental ill-health would appear to not meet the eligibility criteria for NDIS.

Current modelling suggests that up to 200,000 people with mental illness are likely to be ineligible for NDIS individualised funding and not have access to other mental health services (McGrath, 2016). It is reasonable to assume that this figure may be an underestimate, because some people who are living with mental illness do not engage with mainstream (medical) mental health services and therefore are unlikely to have been included in estimates of numbers of people experiencing mental illness (Nicholas & Reifels, 2014).

Data from the trial sites indicates that ineligibility rates for access requests from people with primary mental illness are significantly higher than for other disability types, with 1:4 applications requesting access due to primary mental illness being determined as ineligible compared to 1:9 for applicants across the rest of the Scheme. The reasons for this are unclear and need further investigation.[1]

Preliminary internal assessments of the expected eligibility of Red Cross clients in our Personal Helpers and Mentors (PHaMs) Services to NDIS has been conducted. This review considered how current client indicators might translate into their future eligibility/ineligibility to receive access to the NDIS. Consideration was given to client cases on the basis of their 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. Based on this preliminary assessment, early indications indicate that at least one third of our PHaMs clients would likely be ineligible for NDIS support.

Whilst we understand that continuity of service arrangements will be put in place for these existing clients (contingent on each person applying for and being found to be ineligible for the NDIS), we are

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1 Source: IAC advice on implementing the NDIS for people with mental health issues as at 21 February 2017 from: https://www.ndis.gov.au/about-us/governance/IAC/iac-advice-mental-health

deeply concerned that individuals who are not current clients but who will need services and supports in the future may have no support options. We are further concerned that without continuing community based supports for people with mental ill-health, a significant additional burden is likely to fall on families, communities, health, welfare and justice services, whilst also driving down workforce participation and driving up service costs.

Red Cross recommends that:

1. The NDIA provides a clear definition of the NDIS eligibility criteria for people with psychosocial disability to stakeholders, with a review of the criteria to be conducted as new information emerges around unmet needs for people with psychosocial disability.

2. DSS conduct a review into the eligibility rates for NDIS applicants with a primary mental illness to investigate the high rejection rate of applications for this client group in comparison with applications from people with physical, intellectual and/or sensory disabilities.

b. the transition to the NDIS of all current long and short term mental health Commonwealth Government funded services, including the Personal Helpers and Mentors services (PHaMs) and Partners in Recovery (PIR) programs, and in particular;

i. whether these services will continue to be provided for people deemed ineligible for the NDIS;

Red Cross operates PHaMs at 14 sites across four states and territories, including in rural and remote locations and within disadvantaged communities, as well as Partners in Recovery (PIR) at two sites in Queensland.

Our PHaMs staff report that majority of the client population who identify as Aboriginal and Torres Strait Islander would continue to be without a formal medical diagnosis for their mental health condition. This may reflect the nature of their illness and/or fear of being labelled and stigmatised, cultural factors, and/or the lack of access to specialised mental health services in rural and remote communities. In particular, our PHaMs staff report the following:

- concern for existing clients who have significant psychosocial disability who are ineligible for NDIS support because:
    - they do not have a medical diagnosis of their mental health condition
    - the episodic nature of their illness
- the anticipated gap between the current and future demand and availability of this service type under NDIS funding (Nicholas and Reifels, 2014)
- concern about the lengthy lead-in periods required by some participants with high and complex needs to transition to other services and support
- concern that some people who access a PHaMs service require more intensive support and would benefit from the type of support offered in the NDIS in conjunction with community mental health supports provided by PHaMs

- concern for clients living in regional and remote locations, where block funding arrangements (currently provided by PHaMs) enable economies of scale that provide these harder-to-reach groups with a soft entry point to a variety of professional, community and social supports.

Red Cross has embarked on a number of strategic activities to improve the wellbeing of those experiencing extreme vulnerability due to mental illness and to address the emerging service gaps in the mental health sector through investing in co-design. We have committed our own funds and resources to trial alternative services with people who are experiencing extreme vulnerability, who have lived experience of mental illness and who are at risk of being left out of the new user choice markets.

Commencing in March 2017, the first tranche of our co-design activities will target mental health services in regional and remote Australia: mid-north in South Australia, Goldfields in Western Australia and one regional site in Queensland which is currently being confirmed. Through a joined up partnership approach with service users and their families, volunteers, government, philanthropists and corporates, we will co-create an environment where people living with mental illness can access resources and create strong social connections to achieve economic and social mobility. These activities will include exploring different funding models to ensure the sustainability of services to this most vulnerable client group.

Red Cross recommends that:

3. DSS adopt a co-design approach for the provision of services under the NDIS for people with psychosocial disability related to a mental health condition to ensure they are fit for purpose.

4. DSS maintain the Personal and Helpers and Mentors Support (PHaMS) program alongside the NDIS to provide services for people who are not eligible for the NDIS, until the full implications of the transition of mental health funding are addressed.

5. DSS consider the need for ongoing funding arrangements, including block funding, for services to meet the needs of vulnerable people who are unable to access providers due to cultural sensitivities, lack of family support to navigate the system, those in regional and remote locations or those who are unable to access appropriate diagnosis.

6. DSS invest in further research to identify, understand and address new service gaps as they emerge over the full implementation of the NDIS.

c. the transition to the NDIS of all current long and short term mental health state and territory government funded services, and in particular

i. whether these services will continue to be provided for people deemed ineligible for the NDIS

Approximately 42% of NDIS scheme participants with primary psychosocial disability are recorded as currently receiving services through State/Territory or Commonwealth programs, indicating that State/Territory and Commonwealth funded mental health programs have historically provided significant levels of support to people with mental ill-health [2]. The transition of State/Territory non-clinical community-based mental health services will substantially reduce the availability of services for people with mental ill-health who are ineligible for NDIS.

Further, we are concerned that some vulnerable clients have limited 'systems literacy'. That is, they have difficulty understanding how the complex mental health system currently works and therefore have difficulty navigating it. This is likely to be compounded within the new NDIS service system. A range of factors can act as barriers to people successfully navigating their way to the right services at the right time, and are compounded by poor digital literacy, limited capacity to self-advocate or to promote self-interest, and limited financial literacy required to gain favourable outcomes or optimal support and assistance (Faulkner, Tually & Lewis, 2016).

Therefore, the uncertainty regarding future state/territory government funding for advocacy services is of real concern. People who are not currently in funded disability or aged care services and who are financially or social disadvantaged (e.g. those in the justice system, those living in institutional settings, people who are homeless) are far less likely to be able to access independent information or advocacy supports to assist them to navigate the NDIS. Lack of formal advocacy supports will particularly disadvantage those with cognitive impairments (including some people with mental ill health) and those with few natural supports, who are particularly 'at risk'. Further, only limited advocacy supports are proposed under the Information, Linkages and Capacity Building stream (ILC) within NDIS.

We recommend that the decision by state and territory governments to exit from delivery of mental health services should be identified early and communicated clearly to those who will be affected (clients, carers, and service providers). Timing of such decisions should occur when the details around 'continuity of support' programs have been determined and other service supports are well known. Unless this happens, we believe that there is a very real risk of unintended consequences arising from a period of unprecedented concurrent reform across multiple human services sectors (Quinlan, 2017).

Red Cross recommends that:

7. Governments work with service providers and others to improve understanding about the mental health system among vulnerable groups to ensure that they are able to access supports and services.

8. State and territory governments should work with the Australian Government to ensure that there are no unintended consequences from their withdrawal from mental health services.

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[2] Source: Key Data on Psychosocial Disability and the NDIS as at 30 June 2016 from: https://www.ndis.gov.au/medias/zip/documents/hdb/h14/8799421825054/Attachment-A-Key-Data-on-Psychosocial-Disability-and-the-NDIS-as-at-30-June-2016.docx

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9. NDIS strengthen its communications to stakeholders including service providers, potential clients living with mental ill-health and others to ensure that they are able to access appropriate services in a timely way.

d. the scope and level of funding for mental health services under the Information, Linkages and Capacity building framework

It is difficult to comment on the scope and level of funding for mental health services as the release of the NDIA Community Inclusion and Capacity Development (CICD) Program Guidelines and Information, Linkages and Capacity Building Framework are general and do not provide information specific to mental health services.

However, there is likely to be a significant shortfall in funding for ILC services including in individual capacity building and Local Area Coordination services delivering low intensity or episodic supports given the number of people with disability who are reliant on these services to remain living in the community. Quinlan (2017) identifies that the 'NDIS will make some 64,000 places available to support people with a psychosocial disability, while on the Government's own estimate 230,000 of the 690,000 Australians who experience severe mental illness each year will need psychosocial support'.

Early intervention and prevention services are critical to enabling people living with mental illness to successfully manage their condition, to remain engaged in education, employment, training, and to sustain their social networks. Further, there is recognition that people with psychosocial disability may not see themselves as needing support from the disability sector, and therefore that proactive outreach may be needed to identify these clients (NDIS, 2016). Similarly, the framework acknowledges the critical role of appropriately coordinated and early referrals: "for people with lower level support needs associated with psycho-social disability, ILC will link people into relevant mainstream, clinical and community based supports" (NDIS, 2016, p 9). However, there is not yet any detail provided on how these services might be delivered or funded.

In addition, while the framework acknowledges the benefits of peer support workers for people with psychosocial disability, there is little other detail provided. Local Area Coordination offers the possibility of people with disability being able to access funding to purchase low cost one-off supports and/or seed funding for individual capacity building or initiatives to deliver supports where and how people need them in their local community. Further information is required on how much funding might be available to individuals, whether this funding might be capped or limited to a once-off payment, nor how it might be administered. These are critical issues for people living with a psychosocial disability that is episodic or fluctuating, and who might require more intensive supports during periods of mental ill-health and/or recurrent access to 'seed funding' to re-integrate into their community after episodes of mental illness.

The efficacy of the Information, Linkages and Capacity Building funding will depend on the ongoing presence of community-based services to which people with disability, including people with psychosocial disability can be referred. Without clarity regarding future funding from government, there is a real risk that service providers will exit programs/services which require high levels of flexibility and responsiveness to individual clients living with psychosocial disability.

Red Cross recommends that:

10. DSS should provide targeted funding under the Information, Linkages and Capacity Building stream (ILC) within the NDIS for community based mental health services to support the needs of people living with psychosocial disability.

e. the planning process for people with a psychosocial disability, and the role of primary health networks in that process

Primary Health Networks (PHNs) play a critical role in ensuring access to clinical mental health services (including community-based clinical mental health services) and care coordination for people with mental illness and psychosocial disability, through planning and commissioning of clinical services. PHNs' capacity to highlight local service gaps and influence funding priorities for non-clinical services could make a significant contribution to the service mix within a region. Reliance on PHN planning to estimate the need for funding and services for people with mental illness and psychosocial disability may, however, underestimate the need within a region because a proportion of people living with mental illness will not access clinical mental health services but will require access to community-based mental health services.

The emphasis for PHNs is on the delivery of clinical mental health services within their region however people living with a psychosocial disability usually need 'wrap around' services addressing their housing, income support, education/training, employment and social support. These services are provided by a range of government departments, businesses, not-for-profit providers, and community-based groups. These parallel psychosocial services are a vital adjunct to clinical mental health services and are essential to ensuring participants' wellbeing and community participation. In particular, general practitioners continue to play an important ongoing coordination role, bringing together clinical mental health and community-based support services.

We understand that PHNs have local community advisory councils that include local community groups who provide input regarding their work. These councils must be adequately resourced and supported to mitigate the risk that the services commissioned simply reflect local health service priorities and the existing service mix rather than responding to the needs of local people, including Aboriginal and Torres Strait Islander peoples and other special needs groups. In particular, it is critical that service solutions for people with psychosocial disability are co-designed with them and their families and not for them. Service users need to be consulted and form part of decisions regarding service design and response within each network.

It will also be critical to ensure that the planning process seeks to addresses the service gaps and needs of those in outer metropolitan, rural and remote Australia. Service quality or availability should not be compromised by location. While building online platforms and telephone options may provide some innovative solutions for aspects of care, this cannot be the only option for people outside major metropolitan areas, as quality support often requires person to person services, particularly in the case of mental health services.

Red Cross recommends that:

11. Primary Health Networks (PHNs) should support implementation of the NDIS in the following ways:

(i) seek opportunities to be involved in co-design activities within their local area.

(ii) build their capability in evidence based mental health and co-design to ensure people with mental illness, specifically psychosocial disability and their families are part of the decision making regarding service design and response within each network.

(iii) ensure that Aboriginal controlled Organisations are supported to continue providing culturally appropriate mental health services.

12. Ongoing NDIA planning should address the particular needs of and service gaps of those in outer metropolitan, regional and remote Australia, including Aboriginal and Torres Strait Islander peoples. These needs may include access to face to face services.

g. the role and extent of outreach services to identify potential NDIS participants with a psychosocial disability;

In our experience, the PHaMs program has been effective as a community-based outreach service to people with mental illness who are unknown to clinical mental health services. These clients include people without a clinical diagnosis of mental illness, including those whose illness means that they may have limited insight into their own psychosocial disability, who are resistant to medical services, who fear stigmatisation if diagnosed, who are unable to access mental health services within their local communities, or who culturally view mental illness in different ways. The flexibility of the previous PHaMs guidelines meant that clients without a diagnosed mental illness could access the service and receive appropriate supports, including pathways into clinical mental health services as needed.

Many of our clients live with varying degrees of psychosocial disability and complex social situations arising from their ongoing mental illness and co-morbid medical conditions. Services such as the Assistance with Care and Housing program, (a Commonwealth Home Support-funded program for people aged 50 years and over who are homeless or at risk of homelessness), frequently work with clients whose long-standing mental illness and complex social histories has left them homeless or at risk of homelessness, and who may not have regular contact with mental health or other support

services. The presentation of these clients is due to a housing crisis, but the case worker then facilitates access to services based on the client's needs. This model highlights the importance of clear referral pathways and a 'no wrong door' approach to access to NDIS for participants with psychosocial disability from community-based services (and not limited to clinical mental health services alone).

It is also worth highlighting that those who are most vulnerable and least well supported are often those who are least likely to present to services via 'mainstream' entry points. Our clients include care leavers, members of the Stolen Generation, people in the justice system and others for whom interaction with authorities is extremely confronting. These clients are more likely to flee than to willingly participate in formal assessments or other eligibility screening processes. In these cases, the lengthy lead time needed to gather basic information requirements is likely to preclude the client from services unless their access is facilitated by an advocate well known to the individual (such as a case or peer worker with whom they have an ongoing relationship).

Peer workers are another potential entry avenue for participants with psychosocial disability into NDIS services. Peer workers are individuals who have lived experience of mental illness and who can work alongside participants to inform and guide them based on shared experience and mutual understanding.

Red Cross recommends that:

13. Access to peer workers should be included as a component of outreach services and community based mental health services.

Background Information about Australian Red Cross

Australian Red Cross has been part of the Australian community for over 100 years, supporting the needs of vulnerable people both here and internationally. We were established by Royal Charter in 1914 as part of the International Red Cross and Red Crescent Movement, the largest humanitarian organisation in the world. We are independent of government and are guided by seven Fundamental Principles: Humanity, Impartiality, Neutrality, Independence, Voluntary Service, Unity and Universality. As a Red Cross national society, we also have a unique auxiliary role to public authorities in the humanitarian field.

Red Cross supports and empowers people and communities in times of vulnerability. Our work is underpinned by our extensive network of more than 20,000 volunteers, members and supporters and over 2,000 staff. We provide a range of services and we also seek to influence public policy and public attitudes and behaviours to improve humanitarian outcomes and to build a more humane Australian society.

See attachment also: Red Cross Strategy 2020

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