



ACT  
Mental Health  
Consumer Network

ACT Mental Health Consumer Network Inc.  
The Griffin Centre, Level 2, Room 11  
20 Genge Street, Canberra City, 2601  
P.O.BOX 469, Civic Square, ACT, 2608  
Phone: 02 6230 5796 Fax: 02 6230 5790  
Email: [policy@actmhc.org.au](mailto:policy@actmhc.org.au)  
Website: [www.actmhc.org.au](http://www.actmhc.org.au)

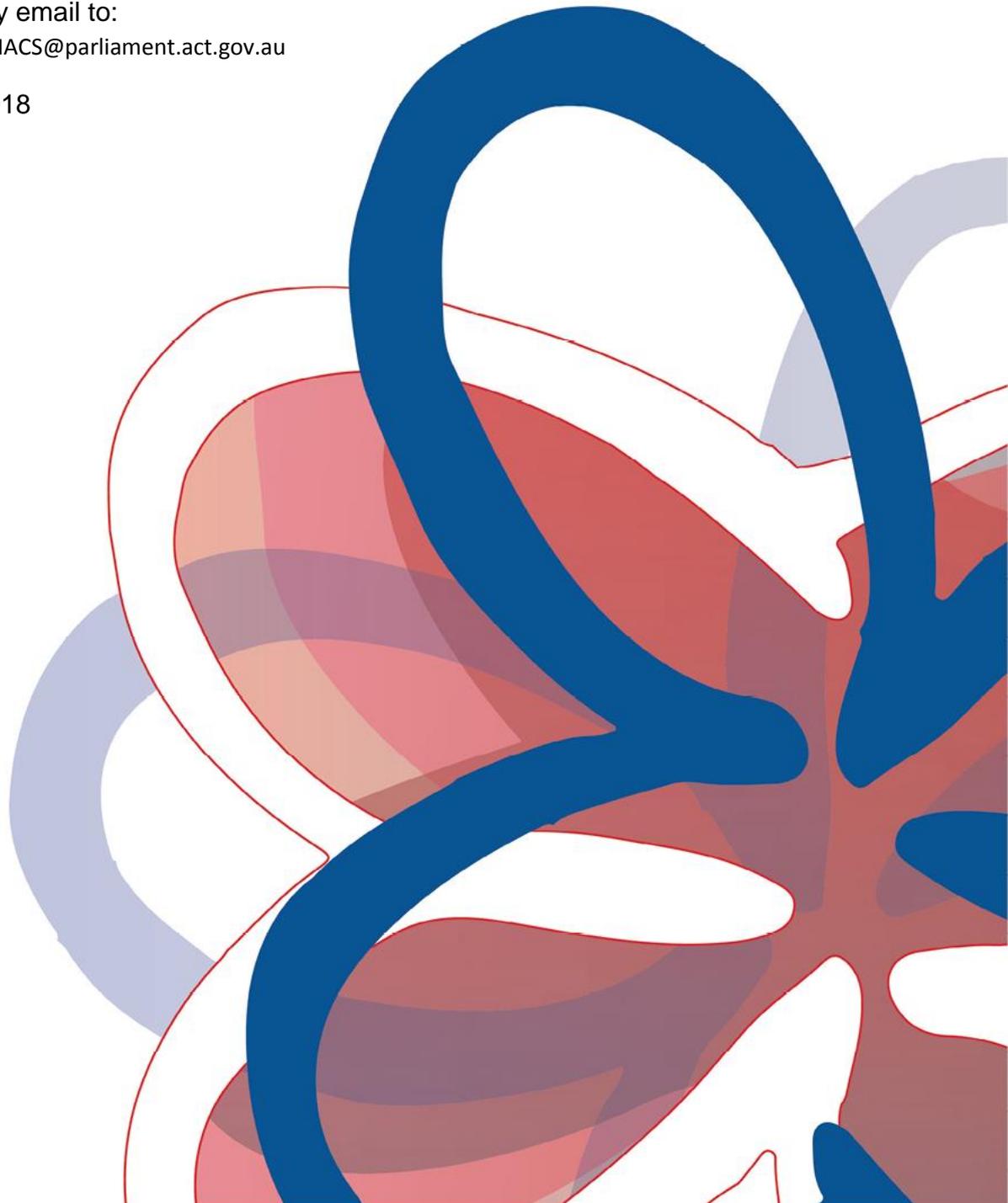
**Submission:**

## **The implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT**

Submitted by email to:

LACommitteeHACS@parliament.act.gov.au

29 March 2018



## **Submission: The implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT**

This submission has been prepared by the ACT Mental Health Consumer Network in response to the invitation from the Standing Committee on Health, Ageing and Social Services.

The ACT Mental Health Consumer Network is a consumer-led peak organisation representing the interests of mental health consumers in the ACT in policy and decision-making forums. The Network is committed to social justice and the inclusion of people with experience of mental illness. Run by consumers for consumers, our aim is to advocate for services and supports for mental health consumers which better enable them to live fuller, healthier and more valued lives in the community.

The Network has held forums and discussion groups for members over the last few years to discuss the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition. This submission draws on the experiences of our members as well as stories shared over a course of time.

### **General comments**

The Network welcomes this opportunity to contribute to the inquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT. It is widely accepted that the NDIS has the potential to transform lives, one mental health consumer made the following statement:

*I would like to say that the actual NDIS packages I have received have been life changing, and I would like to express my deep appreciation for this. I struggled on my own for so many years before the NDIS, it is hard to believe what a difference this support can make.*

Given the above statement, it is important to note that many mental health consumers have experienced numerous challenges with the scheme that require urgent attention as outlined in this and many other submission received for this inquiry.

### **Service gaps**

Since the ACT transitioned into the NDIS, there have been significant changes in the mental health services and programs on offer. The move away from block funding to NDIS funding has meant that some key programs and services are no longer available to mental health consumers who do not have an NDIS package. Two examples of Commonwealth funded services that are currently being phased out,

are the Personal Helpers and Mentors (PHaMs) and Partners in Recovery (PiR) programs. Our members feel strongly that these two programs should continue to be funded for all consumers, regardless of their eligibility for the NDIS or the packages they may have, to prevent people from spiralling into crisis. For mental health consumers the funding source is irrelevant; their concern is for programs such as PHaMs and PiR to continue operating here in the ACT. The following are two members' contributions regarding their experience of loss of service:

*After I had my breakdown, I found attending groups like art classes and badminton assisted me and brought great enjoyment and helped with the challenges of living with mental health problems. These groups had been block funded, but with the advent of the NDIS, this block funding had been withdrawn and put into the pool of NDIS funding. To keep accessing these supports that had made a difference in my life, I had to try and access individual funding through the NDIS.*

*[The] Rainbow was an ongoing activity run by the Mental Health Foundation ACT which is no longer operating due to lack of ongoing funding through NDIS process.*

### **More supports for people with psycho-social disabilities**

Many consumers highlight that the language inherent in the NDIS is primarily deficit orientated and not in harmony with the ethos of recovery in mental health. We have heard of numerous consumers refusing to engage in either testing their eligibility for the scheme or even considering the NDIS as an option in their recovery journey. This is in part because they do not personally identify as having a disability, despite meeting eligibility criteria. Others refuse to engage because they do not want to consider their illness as 'permanent', a key NDIS stipulation, as the term is incongruent with the principles of recovery. We note that in many cases people with psychosocial disability have fluctuating levels of impairment due to the cyclic nature of many mental illnesses. Their fluctuating needs do not fit well into the narrow definitions in the NDIS. The following is a member's contribution regarding their experience:

*The access request forms were the first challenge. The medical evidence form is not designed at all for someone with mental illness. I was given a form from a mental health organisation, the NDIS Evidence of Disability Report form. Unfortunately, the misleading negative wording led to my psychiatrist filling out the complete opposite assessment to the actual facts about my condition. But*

*my advocate informed me that I had not been given all pages of the form! So the shrink didn't read the negatively-worded, greyed-out header 'function... reduced'. And he ticked boxes where I could do something, and crossed them where I couldn't...My application was rejected by the NDIA.*

The Network supports the following recommendation that there should be a “dedicated NDIA lead for psychosocial disability... to work on language and processes around the NDIS to make them more appropriate to psychosocial disability and the recovery model. This should include reviewing and changing the language used in documentation across the Scheme – this will educate staff and make the program more accessible.” ([Mind the Gap: The National Disability Insurance Scheme and psychosocial disability](#). p. 16).

### **Administrative burden**

Network members regularly inform us that the administrative burden to adequately prepare and obtain documentation to apply for an NDIS package is complex and difficult to work through. Many have informed us that without support, the administrative burden would have been too much bear. Our members have expressed their frustration with NDIA staff who oftentimes do not seem to understand the issues that people with psychosocial disability face. One member wrote the following regarding their experience:

*...I would like to ask that something be done to improve the NDIA organisation itself. Even though I am a very happy client with perfect services, I have experienced great frustration and distress through what seems to be incompetence, including:*

- *The NDIA losing a very private document I had sent them about my mental health*
- *Being given completely false information that upset me greatly*
- *Not being told to have professional reports and a support person for reviews*
- *Being contacted via email during the Christmas shutdown period and only being given a few days to respond*
- *Being communicated with what seems to be threatening language eg “if you do not respond by this time your appointment will be invalid”*
- *Leaving messages that are not responded to, including using the email feedback/complaints that was never answered*
- *My Coordination of Support hours being used up by the service provider waiting on the phone for hours with the NDIA and no resolution before the hours expired*

*These are just an indication of the problems encountered when dealing with the NDIA and I believe it creates great distress for us mental health consumers. I am happy however that I have had face to face review meetings, which decreases my anxiety, and I believe this should be considered for all mental health consumers – phone interviews are just too impersonal and difficult to communicate properly. But it should be made clear that ideally a support person should be present, and that review reports from professionals should be provided at the review.*

As indicated above, there are numerous communication issues for those seeking information regarding the NDIS. Furthermore, many people have been left on hold for long periods of time; others have been left waiting for responses to emails for months. There is a strong need for courteous people with knowledge of the NDIS and psychosocial disability to be handling NDIS phone and in-person support. The Network supports the recommendation that there could also be a role for a peer-support group to take on the role of communicating with people with psychosocial disability regarding the NDIS.

### **Review of plans**

The Network is aware of NDIS participants losing a significant proportion of their NDIS package through the review process, with ill-informed explanations offered. Many have informed us that there is a need for greater transparency and consistency of reasons given. For people with psychosocial disability, such decisions have negative health and wellbeing consequences.

### **Eligibility assessments**

Many consumers with severe and persistent mental illness on the Disability Support Pension with complex needs have been found ineligible as a result of inconsistent and poor quality assessment. In this way people with psychosocial disability are falling through the cracks despite the promises of supports through the NDIS.

### **Conclusion and recommendations**

Overall, the Network agrees that the NDIS has the capacity to transform the lives of mental health consumers for the better. However, there are numerous challenges with the implementation of the scheme as outlined in this submission and others submitted for this inquiry. Below are a number of recommendations that are important to the ongoing improvement of service systems for people with psychosocial disability:

1. The territory directorate of health and the federal government must work collaboratively to continue funding flexible programs for people living with a mental illness who will not be eligible for the NDIS;
2. Person-centred supports need to be developed by both the NDIA and existing services to assist individuals through the application process;
3. Professional development for NDIA staff to develop their understanding of the complexity of psychosocial disability; and
4. The ACT government should support and foster the mental health and psychosocial disability workforce, including peer workers, with training and scholarships.

The Network welcomes the opportunity to speak to the members of the Inquiry about our submission should the Committee require further information.