22 February 2021

Minister for the NDIS

Stuart Robert

I write on behalf of Peninsula Carer Council Inc. (PCC), a charitable community organisation.

We recognise consumers, carers and families as experts in the care of an NDIS participant and urge the Minister to ensure much wider consultation occurs.

We recently celebrated 16 years of building strong bridges where carers of people with a mental illness, consumers, professional workers and the wider community can walk and work together with mutual respect and understanding. The PCC provides support, information and advocacy to Carers (family and friends) on the Mornington Peninsula. In fulfilling this mission on the Mornington Peninsula Victoria, the PCC is currently represented on committees of Peninsula Mental Health and Community Services. We have a membership of 149 people and provide monthly support group meetings, morning coffees, carer events and a 1300 telephone service to carers.

As dedicated carers of family members and friends with severe mental illness, we seek to provide NDIA with feedback on proposed changes to the *National Disability Insurance Scheme Act 2013* and what these changes will mean for participants in order to deliver a better and fairer experience for all people with disability accessing the NDIS and participants already in the Scheme. In particular our comments relate to

1.Consultation paper: access and eligibility policy with independent assessments

2.Consultation paper: planning policy for personalised budgets and plan flexibility

As carers who have worked incredibly hard to advocate for access to NDIS and for better plans and support in packages for loved ones, we write to express our concerns with the introduction of Independent Assessments. From our experience we do not believe that the proposed independent assessments with the tools listed can create a complete picture of how a person with severe, enduring chronic mental illness, or episodic mental illness, manages everyday tasks and activities. Valid, accurate assessments of complex persons come from multidisciplinary teams of clinical and allied health professionals who are known and trusted by the carer and care recipient, and, who observe the person over time with essential information from carers who can provide answers to assessment questions that can’t be “Yes or No” but describe the nuanced contextual information needed.

It has been recognised for decades that no illness causes more disability that Schizophrenia. Adjunct Professor John Mendoza quotes employment data indicating less than 10% of those with schizophrenia have any employment, which is the same incidence as in 1995. Often antipsychotic medication prescribed causes deterioration in physical health and contributes to a lower life expectancy. The principle “do no further harm” to this vulnerable group of people with psychosocial disability is relevant to the proposed changes to the NDIS.

A recently released study from a large academic medical centre in New York concluded that a diagnosis of schizophrenia ranked behind only age in strength of an association with mortality in patients with COVID 19. The principle “do no further harm” to this vulnerable group of people with psychosocial disability is relevant to the proposed changes to the NDIS.

As carers, we want to see comprehensive, integrated and holistic care with reasonable and necessary supports for participants in NDIS who have choice and control, and, lifetime support in the decisions about their life and needs. We do not want to see an ill-considered piece of legislation that further entrenches disadvantage to the most vulnerable people with psychosocial disability who may also have dual disability and multiple physical co-morbidities. As mentioned in the points below, an independent assessor in this instance may not have the expertise to gauge the impact of experiencing any or all of the following features of their psychosocial disability: cognitive impairment, paranoia, hallucinations, delusions, lack of insight and reclusiveness. Yet when asked questions by an independent assessor this person will say “I’m fine”. How does an assessor grasp the severity of the impairment and functional impact? How does the assessor interpret responses to the participant’s questions as a stranger, a person unknown to them or their carer? How does an independent assessor determine the appropriate level of funding relating to goals and supports required to achieve goals?

In addition to the discussion above the PCC would like to add the following points for further consideration on the proposed changes.

**1 Lack of consultation**

The PCC believes that there has not been adequate consultation with stakeholders in the mental health sector – consumers, carers and health professionals about the proposed changes to the access, assessment, planning and funding processes, or how they will be implemented. The PCC is aware that this is a complex area but feels that the documentation and process to date does not adequately address this complexity and the potential impact of the changes.

The PCC fully supports the statements from the Mental Health Australia Policy Paper

“The NDIA should undertake genuine consultation with psychosocial disability sector stakeholders, and most importantly people with psychosocial disability, their families and carers, on the implementation and design of Independent Assessments.

“The NDIA should engage with people with psychosocial disability, carers and other key mental health sector stakeholders to build flexibility, choice and control into the Independent Assessment process”.

**2 Lack of transparency**

With regard to the assessment process, the PCC believes that there is a lack of transparency and accountability regarding the participants and how the decisions are made: decisions which will have a lasting impact on their quality of life.

There has been little information available about how the assessment decisions will be made and the key factors driving the decision-making process.

Two pilots were planned to work out what works well and what needs to be improved. The first pilot has been run but to date there has been no information released publicly about the outcomes of the pilot. The PCC believes that consumers, carers and other stake holders should receive this information.

**3 Access to NDIS Process**

Eligibility for the NDIS will be determined by information required from the Access Request form (which is very basic) and the independent assessment.

The information paper “Improving the National Disability Insurance Scheme” states “From mid-2021, the outcomes of an independent assessment will be a primary source of information to help the NDIA determine whether a person with a disability is eligible to receive supports under the NDIS” (p 14).

There is little information about the weighting to be used when considering Independent Assessments except to say it is a primary source. There is little information about how any supporting information is to be used in this process.

This is of particular concern when the documents state that the outcome from the independent assessment is unreviewable.

The PCC believes that more detailed information from the person’s health professional should be included in this process or else the decisions will be unfair and inadequately informed. With the development of a severe mental illness, it often takes many years for a diagnosis to be made. By the time a person and/or carer has reached the stage whereby an application to access the NDIS is made, there is a lengthy case history of assessments, reports and efforts to get help from GPs and services. This is essential information for NDIS access.

If the NDIA is concerned about consistency then health professionals could use a standard form with open ended questions for qualitative information.

The PCC does not understand how such an important decision can be made about a complex disability without qualitative information.

**4 Independent Assessments**

The PCC believes that given the significance of the independent assessments, there will not be enough time to capture the necessary information. The environment will not be conducive to a person feeling comfortable about revealing often quite personal information. This will be particularly challenging for people who suffer from PTSD, anxiety or paranoia.

The PCC is also concerned that without additional qualitative information from health professional, the questions from the tools will not capture complexity and variability of mental illness.

**5 Appropriate Knowledge and Skills of Independent Assessors Psychosocial Disability ?**

Carers have a lack of confidence that independent assessors will have the appropriate skills or knowledge. Having a qualification is one thing but to have experience and knowledge of this complex area of disability is crucial.

Lack of understanding of the complexities and variability of mental illness is a constant source of frustration for carers. The PCC is concerned that assessors will not have adequate skills and training to fairly conduct the assessments.

**6 Funding**

According to the documentation, Independent Assessments will be used to determine the level of funding. The PCC questions the adequacy of these assessments to determine the supports that a person will require. This is central to the Person Centered approach which underpins the intention and philosophy of the NDIS.

In addition, given that the independent assessment is used to determine funding, it does not seem right or fair that there is no appeal or review process for this.

However, the PCC is pleased to see that funding will be more flexible.

**7 Review Process.**

The documentation states that “The **access decision** remains a reviewable decision and the applicant can request an internal review and then appeal the decision at the Administrative Appeals Tribunal (AAT).” (Consultation PB Access Eligibility Policy, p 23)

It is not clear from the documentation which parts of the access decision would be reviewable especially given the independent assessment (which is a major part of this decision) is not reviewable. The PCC finds this most unsatisfactory given our carers’ experience of the difficulty in understanding the nuances and complexities of this type of disability. For some it will be straight forward but for many it will not.

In regards to the independent assessment, the documentation simply states that there will be a complaints process for those that “are dissatisfied with an independent assessment, their assessor, or the assessor organisation” but there is no detail about the process, under what circumstances it can be used and the possible outcomes.

**8 Quality Assurance**

If the NDIA is to use standard tools, these should be reviewed regularly to confirm their appropriateness or otherwise to mental health.

Continual review and improvement is now a standard organizational practice in business and government.

According to the Consultation PB Access Eligibility Policy, the NDIA is …” developing a quality assurance framework for the delivery of independent assessments. This will ensure they meet the standards under relevant professional and regulatory frameworks. “. (p 23) Surely consumers, carers and associated services should contribute to this Framework.

This submission refers to the following: -

**Consultation papers for how the NDIS works for 7-65 year olds**

**Consultation PB Access Eligibility Policy**

**Access and eligibility policy for independent assessments**

**Planning policy for personalised budgets and plan flexibility**

**Improving the national Disability Insurance Scheme – DSS information paper (Nov 2020)**

**Mental Health Australia Policy : National Disability Insurance Scheme Independent Assessments**