



JFA
Purple Orange

JFA Purple Orange Submission

In response to the Joint Standing Committee on the National Disability Insurance Scheme inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition

Submitter details

JFA Purple Orange
104 Greenhill Road
Unley SA 5061 AUSTRALIA

Telephone: + 61 (8) 8373 8333

Fax: + 61 (8) 8373 8373

Email: admin@purpleorange.org.au

Website: www.purpleorange.org.au

Facebook: www.facebook.com/jfapurpleorange

Contributors

Mikaila Crotty, Project Officer

Jackie Hayes, Leader Social Policy and Initiatives

Robbi Williams, CEO

About the Submitter

JFA Purple Orange is a non-government, social profit organisation. Anchored on dialogue with people living with disability, their families, service providers, government and other stakeholders, we seek to identify policy and practice that has the prospect of advancing peoples chances of a good life. Our work is anchored on the principles of Personhood and Citizenhood. Our work includes research, evaluation, capacity building, consultancy, and hosted initiatives.

© January 2017 Julia Farr Association Inc.

Contents

1.0 Summary	3
2.0 Purpose	4
2.1 Introduction.....	4
2.2 Key Values	4
3.0 Approach	5
4.0 Key Issues	6
Key Issue 1- Support for family members and other informal supporters of individuals with psychosocial disabilities related to a mental health condition ineligible for NDIS funding	6
Key Issue 2 -The assessment of eligibility to NDIS funding for individuals with psychosocial disabilities related to a mental health condition and ensuring appropriate training of staff involved in determining eligibility.....	7
Key Issue 3 -The risk of closure of current psychosocial disability services.....	8
5.0 Conclusion and Recommendations	9
6.0 Request to meet	11

1.0 Summary

The National Disability Insurance Scheme (NDIS) is a critical social welfare reform in Australia and presents a genuine opportunity for people living with psychosocial disability to receive the support needed to deliver transformational benefits. These are benefits that assist the person to build confidence, to build knowledge and skill, to build access to ordinary mainstream resources like other people, to build personal networks, and to find genuine fair-waged work.

Such support has been lacking in the past, and even current services are struggling to provide for people living with severe mental illness. The sector has identified a need for an NDIS that is consistent with contemporary recovery-focussed practice (an acknowledgement that a psychosocial disability can be episodic and may not be permanent) and there is a need to expand services rather than reduce them.

We know that a significant number of people will not be eligible for the NDIS and this raises questions about what support and services will be available as Commonwealth funded programs such as Personal Helpers and Mentors (PHaMS), Partners in Recovery (PIR) and Day to Day Living are absorbed into the scheme.

It is hoped that the NDIS principles of continuity of support and of no disadvantage will prevail but this will be of little comfort to those people who have already fallen through the gap and are not currently receiving any services.

Psychosocial disability has been defined by Mental Health Australia as:

*Psychosocial disability is an internationally recognised term under the United Nations Convention on the Rights of Persons with Disabilities, used to describe the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives.*¹

Furthermore, Mental Health Australia emphasise that the term psychosocial disability includes the 'social consequences of disability'- the effects on someone's ability to participate fully in life as a result of mental ill-health. This social consequence could impact on individuals' opportunities to take part in social, educational or training activities.

Psychosocial disability differs from physical and sensory disabilities in significant ways. These differences may affect people's ability to seek and access services through the NDIS,

¹ <https://mhaustralia.org/general/getting-ndis-right-people-psychosocial-disability>

and their eligibility for them. For instance, people with a psychosocial disability may be less likely than people with other types of disability to identify themselves as living with disability and seek support. This is important to bear in mind within the framework of the NDIS as the umbrella category of “disability” may not be a category that people with mental health related conditions readily identify with.

2.0 Purpose

JFA Purple Orange welcomes the opportunity to contribute to the Committee’s Inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition. This submission is based on the views of JFA Purple Orange as well as stakeholders and those who attended the Partners in Recovery (PIR) Community forums held in Adelaide in February 2017 as part of a consultation regarding the provision of NDIS services for people with psychosocial disabilities relating to a mental health condition.

2.1 Introduction

JFA Purple Orange is the social policy agency of the Julia Farr group, a trio of social profit, non-government organisations based in South Australia, working to improve the life chances of people living with disability. The Julia Farr group (JFA Purple Orange, Julia Farr Housing Association, and the Julia Farr Trust and Julia Farr MS McLeod Benevolent Funds) and its predecessor organisations have been involved with the disability community, older people and other vulnerable groups for more than 130 years.

We are an independent, non-government organisation that fosters innovation, shares useful information, and promotes policy and practice that support and improve the life chances of people living with disability.

JFA Purple Orange is not a service provider – we deliver research, evaluation and information services anchored upon the stories and experiences shared by people with a lived experience of disability and others in their lives. As such, we feel we are ideally positioned to offer comment.

2.2 Key Values

The work of JFA Purple Orange is anchored on the principles of *Personhood* and *Citizenhood*.

As set out in our Model of Citizenhood Support², a good life is characterised by such valued roles (termed Citizenhood) and by the decisions we make (termed Personhood). A good life largely depends on the availability of life chances – the assets and opportunities available to a person.

² Williams, R. (2013), *Model of Citizenhood Support: 2nd edition*, Julia Farr Association Inc, Unley South Australia

Unlike formal citizenship of a country, Citizenhood is a dynamic experience: it can rise and fall depending on a person's circumstances. The extent to which any person can naturally take up Personhood and Citizenhood is influenced by the presence of circumstances that can adversely impact on the person's capacity to build authorship of their own lives and the person's capacity to take up valued roles in community life and the economy.

Aside from the need to increase the total amount of funds available for disability support, the two values that have driven the emergence of the NDIS have been

- Each person having *control and choice*, taking up authorship of their own life
- Each person *participating in community life and the economy*, taking up valued roles that bring genuine community membership.

These have an excellent fit with the notions of Personhood and Citizenhood. The NDIS is founded on a framework that promotes empowerment in people living with a disability.³ As such, JFA Purple Orange believes that all eligibility and access to services provided by the NDIS must be anchored on principles that will assist people accessing NDIS to feel empowered and supported, to take up valued roles in mainstream community life.

3.0 Approach

Our submission focuses on the values, matters of concern and experiences of JFA Purple Orange drawn from:

a) A review of documents

We canvassed the available sources published in the public domain on the topic of NDIS services for people with psychosocial disabilities related to mental health conditions. This included policy papers, government reports, media notices and published articles. From this body of material, we undertook analysis and generated a list of key issues.

b) Consultation with representatives of key services

This submission is based on the perspectives and views of the social policy agency JFA Purple Orange. These views are drawn from the perspectives of a number of stakeholders in the sector and approximately 50 Members of the public who attended the Partners in Recovery (PIR) Community forums on mental health and the NDIS held in Adelaide in February 2017.

The issues of primary interest to JFA Purple Orange are those outlined in three of the Inquiry's Terms of Reference:

- a) the eligibility criteria for the NDIS for people with a psychosocial disability;

³ NDIS Values, Capabilities, and Behaviours factsheet, <https://www.ndis.gov.au/document/our-values-capabilities-and-behaviours>

- 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;
- 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.

4.0 Key Issues

Key Issue 1- Support for family members and other informal supporters of individuals with psychosocial disabilities related to a mental health condition ineligible for NDIS funding

JFA Purple Orange is aware of the crucial role that family members and supporters play in the lives of individuals with psychosocial disability related to a mental health condition. The pressure placed on family members and other informal supporters can be extreme, in part due to the significant role played by this group of people, such as ensuring an accurate assessment and provision of services that meet the individuals' needs. It is noteworthy that the role of family members and other informal supporters will be pivotal for many individuals with psychosocial disability related to a mental health condition as they apply for NDIS support.

A significant amount of assistance from a family member or supporter will be required for many people to ensure that the assessment captures the impact of their disability on their everyday functioning and that the resulting support plan is appropriate to the participant's needs. Therefore, the role of the supporter cannot be downplayed. The NDIS support plan must also be adequate for maintaining the sustainability of the caring relationship; hence the development of this support plan with input from the family member or supporter is crucial.

It is likely that the process of applying for NDIS support for this group of people will bring with it a great deal of stress and additional demands to the family member and supporter population found within this cohort.

We recognise that it is possible that up to 100, 000 individuals who currently receive government-funded services may lose these supports following the implementation of the NDIS in 2017.⁴

⁴ <http://www.theaustralian.com.au/national-affairs/health/100000-mentally-ill-lose-ndis-cover/news-story/3f2363653fc5e86044f4ae2116395273>

This is a significant figure and it means that there will be a large group of individuals relying on other means of support. JFA Purple Orange has concern for the wellbeing of consumers who do not fit the requirement of having a 'permanent disability' and their supporters. For these individuals, critical services which they have come to rely upon may be taken away and this places a greater demand not only on the family members and supporters but on the greater state and commonwealth healthcare system.

During the PIR consultation, family members voiced their anxiety about overburden, burn out and extreme strain on family supporters of people deemed ineligible for NDIS support. Anecdotal evidence includes those in a caring and supporting role being concerned about a risk of abandonment (the supporter may walk out on the role), a risk of physical and mental health crises (supporter may become too sick to continue in the role) and a pervasive fear regarding the future care for the person when current family members and supporters are no longer alive.

JFA Purple Orange recognises that these concerns are legitimate and reiterates the need for careful planning and transition to alternative support systems for individuals with a psychosocial disability related to a mental health condition who are found to be ineligible for NDIS support.

Key Issue 2 -The assessment of eligibility to NDIS funding for individuals with psychosocial disabilities related to a mental health condition and ensuring appropriate training of staff involved in determining eligibility

JFA Purple Orange recognises that the NDIS use the term "significant and permanent disability" in regards to eligibility criteria for gaining access to services. This is problematic in relation to psychosocial disability or mental illness as these conditions are known to fluctuate over time and therefore be of an episodic nature.

We are aware that the National Disability Insurance Agency (NDIA) has clarified that episodic illness may be considered permanent. However, it is concerning that individuals will be judged on their presentation at the time of assessment if they are to qualify for NDIS support. The episodic and fluctuating nature of mental illnesses may mean that many people are deemed ineligible simply based on the timing of an assessment rather than an accurate reflection of their lived experience of psychosocial disability. For example, people experiencing 'bad days' or periods of acute symptoms who can otherwise live independently may not fit the criteria of psychosocial disability.

There are often several other factors that people with a psychosocial disability live with, which create additional complex circumstances in their lives. These include factors such as homelessness, poorer physical health, and fewer social connections or networks. These factors can lead to less contact with health and community services and this may mean that this group of individuals may not be readily identified as potential NDIS clients.

There needs to be an acknowledgement that for people with mental health issues, functional impairments can be on-going or “permanent” even when the symptoms of the mental health condition are not on-going or permanent. For example, the disability can be present even when the symptoms of the condition are not active or present. JFA Purple Orange recognises that ‘functional impairment’ is the term used in the eligibility criteria and this is a more useful focus than simply diagnostic criteria. However, we are concerned by the possibility that formal assessment processes to determine eligibility for NDIS services for individuals with psychosocial disability may be more focussed on diagnostic information.

Upon consideration of assessment methods related to NDIS eligibility for people with psychosocial disability, JFA Purple Orange would like to formally recommend for a standardised approach to assessment. This includes recommending a standardised suite of appropriate assessment instruments for determining impaired functions in individuals with mental illness and psychiatric conditions. We are aware that effective use of these types of assessment instruments is highly contingent on the skills and knowledge of the assessor and particularly their knowledge of psychosocial disability and mental illness.

Given the huge number of assessments that will be needed to be undertaken with individuals in this category, we remained concerned that some staff undertaking such assessment may not have adequate experience in working with mental health clients or exposure to interpreting specific assessment findings. Our concerns remain in line with those of Quinlan⁵ who outlined similar concerns and emphasised the need for specifically trained mental health workers to lead the assessment processing, stating “we must ensure the expertise of the mental health workforce is not lost or dumbed down.”

JFA Purple Orange agrees with this statement and furthermore believes that it is critical to provide support for private or sole providers contracted via the NDIS to ensure that they maintain their skills through a targeted and standardised approach to ongoing professional development, specifically in mental health training.

Key Issue 3 -The risk of closure of current psychosocial disability services

There is a real risk that some local psychosocial disability services, especially those that are community-focused not clinically-focused, will be at significant risk of closure because their state/territory funds will dry up. The funds will dry up either because:

- a) explicit calculations underpinning bilateral agreements mean those funds are gathered up as part of the agreement and generically transferred to NDIS, or
- b) implicit assumptions at the state/territory level that anything relating to disability and psychosocial disability service delivery is now the business of the NDIS.

⁵ Quinlan, R. 2014. Getting the NDIS right for people with psychosocial disability. *Mental Health Australia*

There is no guarantee that local service providers can bridge the uncertain funding gap between the close-off of local funding, and the arrival of individual purchases by NDIS participants. Also, there is no guarantee that all current users of such local services will be eligible for an NDIS individualised funding package (IFP). Given the ILC has a much smaller pool of funds, it is arguably more likely to be drawn to shorter-term investments that hold the promise of measurable capacity-building, quick links into community networks, and lower-cost sustainable information services (such as websites or phone apps). These short-term investments frameworks as described above do not necessarily fit well with meeting the typical situations and required services at mental health drop-in centres.

Similarly, issues exist with reason (b) regarding implicit assumptions at the state/territory level that anything relating to disability and psychosocial disability service delivery is now the business of the NDIS. It cannot be assumed state/territory government staff involved in commissioning have a detailed understanding of the role such local services can play within the health and social services system. To illustrate, we would like to share an example from a social audit JFA Purple Orange conducted in ACT. We observed how one local mental health service delivered very effective mental health first aid and grassroots 'case management' as needed. This service response on that day helped avert the immediate risk of higher costs local health services such as an ER presentation and a mental health inpatient admission while also averting the risk of housing breakdown through eviction. As such services operate in a low key way, they are often 'under the radar' and the impact of their work is not always well-known by government funders.

However, the absence of such services can create increased cost pressures in state-territory health, housing and law enforcement, and these cost pressures will likely outweigh the costs of the service, let alone the human cost of poorer clinical and/or social outcomes.

JFA Purple Orange recommend that bilateral agreements be reviewed to test the assumptions underpinning the inclusion of the costs of such local services, and that the NDIS work closely with states and territories to ensure the extent of the above 'gap' risks is fully known, scoped and properly managed before local funding is withdrawn.

We further recommend that best practice in relation to this situation could be developed by a focussed consultation within the ACT. This way, methodologies jointly run by the territory government and the NDIA could be properly tested with formal input from consumers and families and community leaders.

5.0 Conclusion and Recommendations

Good supports are an important ingredient for people to take up valued roles as members of their community and contributors to the economy. The NDIS aims to fund supports that advance its participants' chances of moving into rich and meaningful lives. This is consistent

with the National Disability Strategy and the United Nations Convention on the Rights of People with Disabilities.

This means that the support arrangements for each person need to deliver *transformational* benefits. This takes vision, highly intentional planning, belief in the person's intrinsic value, and deep respect for the person's central role as the decision maker in their own life. This is as true for people living with a psychosocial disability related to a mental health condition as it is for any other person.

We know that a significant number of people will not be eligible for the NDIS and this raises questions about what support and services will be available.

The key points emerging from the submission are:

1. A recommendation that services and supports be decided on an individual basis and on what is reasonable and necessary for the person living with psychosocial disability rather than on a diagnosis of permanency.
2. A recommendation for provision of services to support family members and supporters of individuals with psychosocial disabilities related to a mental health condition during and following the roll out of NDIS services.
3. A recommendation that individuals with psychosocial disabilities related to a mental health condition who are undergoing assessment for eligibility of provision of NDIS services, be assessed using appropriate assessment methods and that assessments are carried out by staff members who hold an accredited qualification in mental health.
4. A recommendation for a uniform and standardised training program to be provided to NDIS staff involved in assessment and provision of services to individuals with psychosocial disabilities related to a mental health condition. This training package needs to provide appropriate training and skills development tailored to identifying the needs and individual circumstances of people living with a mental health condition
5. A recommendation for a review process to be established to test the assumptions underpinning the inclusion of the costs of local services, and that the NDIS work closely with states and territories to ensure the extent of 'gap' risks following the absence of some services is fully known, scoped and properly managed before local funding is withdrawn.
6. A recommendation for a targeted consultation process to occur within the ACT to establish best practice in relation to this area, including involvement from consumers, families and community leaders.

6.0 Request to meet

We would welcome the opportunity to provide additional information as required. We would also value the opportunity to meet with the Select Committee to discuss the submission contents in more detail.

For further information about this submission, please contact:

Robbi Williams
Chief Executive Officer
Julia Farr group
Phone: (08) 8373 8333
Email: admin@purpleorange.org.au