



Purple Orange

**Submission to SA Social Development
Committee inquiry about the provision of
services for people with mental illness under
the transition to the National Disability
Insurance Scheme (NDIS)**

October 2018

About the Submitter

JFA Purple Orange is an independent, social-profit organisation that undertakes systemic policy analysis and advocacy across a range of issues affecting people living with disability and their families.

Our work is characterised by co-design and co-production, and includes hosting a number of user-led initiatives.

Much of our work involves connecting people living with disability to good information and to each other. We also work extensively in multi-stakeholder consultation and collaboration, especially around policy and practice that helps ensure people living with disability are welcomed as valued members of the mainstream community.

Our work is informed by a model called *Citizenhood*.

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1. Summary and recommendations

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 skills, 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 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 the need to expand services rather than reduce them.

However, the NDIS will not be able to cater for all South Australians living with severe mental illness or psychosocial disability; therefore it is crucial to consider the South Australian mental health services as a whole and not just from a view that is NDIS-centric.

We recommend:

1. that a solid investment be made from the South Australian Government in increasing the peer workforce for people living with psychosocial disability
2. that the South Australian government undertake a thorough gaps analysis in regards to mental health services across south Australia to determine how these gaps can be addressed at the state level
3. that the South Australian government invest in funding models similar to that previously offered by the Partners in Recovery programs that provide allocated

resources and a dedicated point of contact to support people living with mental illness and psychosocial disability support; and

4. that the South Australian government undertake work to identify the understated prevalence of mental illness and accompanying need for mental health services within South Australians living with disability, particularly NDIS participants for whom psychosocial disability or mental illness is a secondary or subsequent impairment

2. Introduction

JFA Purple Orange welcomes the opportunity to contribute to the Committee's Inquiry into the provision of services for people living with mental illness under the transition to the NDIS. This submission is based on the views of JFA Purple Orange as well as those of the stakeholders we support through peer network and hosted initiatives.

JFA Purple Orange is 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.

2.1. 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 Support¹, 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.

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

¹ Williams, R. (2013), *Model of Citizenhood Support: 2nd edition*, Julia Farr Association Inc, Unley South Australia
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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 the empowerment of people living with disability.² 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. 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. We analysed this body of material and generated a list of key issues.

b) The South Australian disability community

² NDIS Values, Capabilities, and Behaviours factsheet, <https://www.ndis.gov.au/document/our-values-capabilities-and-behaviours>

JFA Purple Orange host several peer group initiatives for people living with disability across a broad range of age groups.

The issues of primary interest to JFA Purple Orange are those outlined in the following Terms of Reference:

4. The effects on South Australians with mental health issues who are deemed ineligible to receive NDIS funding;
6. The effects on South Australians with mental health issues undertaking the application process for the NDIS;
7. Any other relevant matters

Therefore, this submission mainly focusses on issues identified by JFA Purple Orange that are connected to these Terms of Reference.

4. Key Issues

4.1. Key Issue 1- The access processes for obtaining mental health services for people who live with psychosocial disability

The process and eligibility requirements that are being placed upon South Australians who live with psychosocial disability as they navigate current systems are complex. For example, it is necessary for people seeking mental health services to understand the eligibility of a range of systems and services. These include the NDIS, the Primary Health Networks and the state-funded mental health services. This is in addition to mainstream services that can be a critical part of managing mental health such as GP services and specialised mental health practitioners. There are specific roles, eligibility criteria and referral pathways attached to the access path for each of these services. It is known that many South Australians experiencing mental illness will not qualify for services offered via the NDIS. However, these same people are still very likely to require ongoing support and will continue to live with psychosocial needs that may remain unaddressed and therefore grow in significance.

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This suggests a strong need to move away from a system oriented around the NDIS when it is clear that many people living with mental illness and/or psychosocial disability won't be eligible for NDIS funded supports. Rather, there needs to be investment at a state level of a funded model of support that can offer South Australians a resourced service to assist them to navigate mental health services. We recommend that a thorough gaps analysis be undertaken in order to identify where the gaps are for South Australians living with mental illness who are ineligible for funded support via the NDIS.

4.2. Key Issue 2- The access process for obtaining entry to the NDIS for people who live with psychosocial disability

The process for accessing the NDIS via the existing generic access form remains as a challenge for people living with psychosocial disability for a number of reasons. JFA Purple Orange is aware that for individuals not transitioning from existing services it is necessary to gain access to the Scheme via an access form that needs to be completed by a treating practitioner and then submitted to the NDIA. Although changes to the Scheme for people experiencing psychosocial disability are underway, we believe that these changes will not result in any alterations to the initial access process nor introduce a tailored access form that specifically relates to psychosocial disability.

We can identify a number of issues for people living with psychosocial disability with the current access request form and associated Supporting Evidence form. These include:

- a) There is no guidance provided from the NDIA as to who the most appropriate practitioner is to complete the form(s) for people living with psychosocial disability who wish to access the Scheme. This places the onus on the individual to approach a practitioner (e.g. GP, psychologist, psychiatrist, OT), have the appropriate forms ready for completion and be prepared to assist with providing the information required. This is likely to be a difficult process for many people who live with psychosocial disability to navigate for many reasons including that the nature of their

illness(es) may mean they do not have a consistent treating practitioner or that it may be challenging for them to remember to bring the paperwork to be completed.

- b) The design elements of the NDIS access form and Supporting Evidence form necessitate free text entry by a treating practitioner under the broad categories of mobility, communication, social interaction, learning, self-care and self-management. There is no direction offered to practitioners completing this form as to the amount of information to provide specific examples as they relate to psychosocial function, specific examples of assessments, prompts for past clinical history, or prompts for medication. No readily accessible support guides or documents have been provided to practitioners from the NDIA. This means that the completion of this form is highly dependent upon the expertise of the treating practitioner, their knowledge and understanding of the circumstances of the applicant, their own interpretation of the categories and what is being asked of them within this form and the applicant's ability to submit this to the NDIA for assessment. This process as a whole seems to place a high level of demand on both treating practitioners as well as the applicants themselves with little avenues of guidance or support from the NDIA.
- c) Furthermore, the Supporting Evidence form invites practitioners to supply written support (e.g. a letter) or completed assessments that are relevant to the functional impairment experienced by the applicant. Whilst these options in some circumstances could be useful in order to provide a greater overview of the range of circumstances that an applicant is experiencing, in the context of psychosocial disability it would seem that these options are both confusing and limiting. For instance, there is no guidance as to the specific assessments that would be deemed appropriate. Owing to the fluctuating nature of psychosocial disability and common symptoms of severe mental illness it is likely that many people have not been in a position to have recent nor appropriate assessments conducted. This then places an expectation on the treating practitioner to ensure that any assessment that is

attached to the NDIS Access form is appropriate for the ensuing decision-making process. Similarly, without tailored guidance, a written letter of support must be completed in a way that comments on the areas of functional impairment that the NDIA are basing their access decisions upon. This again leads to confusion and a lack of consistency.

JFA Purple Orange believes that these issues related to the access process and especially the design of the Supporting Evidence form itself have great impact on South Australians with mental health issues undertaking the application process for the NDIS. For many people, they will have few avenues for support in navigating this process. A unique design element of the Partners in Recovery model has been that people living with mental illness have had tailored supports including a dedicated contact point who facilitates additional services as needed. This kind of outreach and facilitation of additional supports is much-needed in a community mental health service delivery model and this is unlikely to be replicated for people accessing the NDIS, let alone for those deemed ineligible. We recommend that greater investment at the state-level towards continuation of a model similar to Partners in Recovery would allow many South Australians living with mental illness and/or psychosocial disability access to resources they need to thrive in these systems.

4.3. Key Issue 3- The effects on South Australians living with mental health issues who are deemed ineligible to receive NDIS funding

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 no disadvantage will prevail but this will be of little comfort to those people who have already fallen through the gaps 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.*³

Furthermore, Mental Health Australia emphasises that the term psychosocial disability includes the ‘social consequences of disability’; that is, 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. JFA Purple Orange sees this as a prime opportunity for state-level investment in a peer workforce to support people living with mental illness and psychosocial disability in South Australia.

Psychosocial disability differs from physical and sensory disabilities in significant ways. These differences may affect people’s ability to seek and access services through schemes such as the NDIS, and their eligibility for them. For instance, people with a psychosocial

³ <https://mhaustralia.org/general/getting-ndis-right-people-psychosocial-disability>

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 are used to identifying as belonging to.

However, there is a growing evidence-base in support of the outcomes that can be reached through a model of support offered by mental health peer mentors and peer leadership.^{4,5} It is still not a standard approach for all South Australian community mental health teams to employ peer workers. It is readily accepted that peer networks can provide significant support to members, as by their nature peer networks require members to collaborate with each other. For many people living with a mental health condition or psychosocial disability, the ability to stay connected to information, resources and other people could be life-changing. Information and knowledge are powerful and enabling tools that help with navigating life circumstances. A peer mentor or leader can provide a useful way to gain more knowledge, information and resources.

In the context of mental health, peer workforce models have been shown to be very effective at establishing connections, acting as a bridge between clients and other staff. The value of peer work is also demonstrated for peer workers themselves, as it provides workers with an opportunity to draw on a difficult experience and inspire others. Peer workers are visible role models that foster hope and inspiration for recovery, especially important for people experiencing mental illness where experiences of isolation are common.⁶

⁴ Employer’s guide to implementing a peer workforce, Peer Work Hub, 2016

⁵ <http://peerworkhub.com.au/the-case-for-peer-work/why-develop-a-peer-workforce/>

⁶ Health Workforce Australia (2014): Mental Health Peer Workforce Study.

JFA Purple Orange recommends an investment from the state government in peer workforce models across the South Australian mental health system. The skills and compassionate perspective of such a workforce offers a unique mechanism to inform and complement the work of other services within a system.

4.4. Key Issue 4- The understated prevalence of mental illness and psychosocial disability among South Australians living with disability

It is widely accepted that people living with disability often face a complex combination of disability and health conditions, resulting in more than simply one disability or impairment. Given this known complexity it is suffice to say that for South Australians living with disability, any specialised health needs are inextricably linked to disability outcomes. This is particularly the case for people living with disability for whom mental illness or psychosocial disability may be considered as a supplementary or secondary impairment to that of their primary disability or health condition. JFA Purple Orange suggests that there is a requirement both from a Scheme such as the NDIS but also at state level to plan specifically to meet the needs of this group within the design of health and service systems.

Therefore, in a wider focus than just the South Australians accessing the NDIS, JFA Purple Orange asserts that there is a largely understated prevalence of mental illness across the cohort of South Australians who live with some form of disability. We are aware for example or many people who have listed a mental illness as a secondary or subsequent impairment on NDIS access forms. Likewise, in our work with people living with disability we are aware that severe and often lifelong conditions such as anxiety, clinical depression and personality disorders often co-exist alongside permanent disabilities. A comprehensive review of population studies looking at the prevalence of mental illness across Australia suggest that in 2014-15, there were an estimated 4.0 million Australians (17.5%) who reported having a

mental and behavioural condition.⁷ Combined with the knowledge that it is predicted that almost half (45.5%) of all adults in Australia will have experienced a mental health condition at some stage in their lifetime⁸, it is imperative that the mental health needs for people living with disability in South Australia are identified and planned for. Currently, it is not readily known the extent to which South Australians who identify as living with disability also live with a mental illness, nor what their mental health service needs are. Therefore, we recommend that a focus is given to the co-existence of living with disability and secondary or subsequent mental illness in order to map the demand across the sector for South Australians living with these co-morbidities.

5. Conclusion

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.

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. Furthermore, the NDIS Bilateral

⁷ Australian Bureau of Statistics (ABS). National Health Survey: First Results, 2014, 15. (ABS Cat.no.4364.0.55.001). Canberra: ABS; 2015.

⁸ Public Health Information Development Unit (PHIDU). An atlas of mental health conditions in South Australia: population patterns of prevalence, risk factors, service use and treatment. Adelaide: PHIDU, 2016.

Agreements appoint the state government to be responsible for services not covered by the NDIS in line with other agreements.

The key points and recommendations emerging from the submission are:

1. that a solid investment be made from the South Australian Government in increasing the peer workforce for people living with psychosocial disability
2. that the South Australian government undertake a thorough gaps analysis in regards to mental health services across south Australia to determine how these gaps can be addressed at the state level
3. that the South Australian government invest in funding models similar to that previously offered by the Partners in Recovery programs that provide allocated resources and a dedicated point of contact to support people living with mental illness and psychosocial disability support; and
4. that the South Australian government undertake work to identify the understated prevalence of mental illness and accompanying need for mental health services within South Australians living with disability, particularly NDIS participants for whom psychosocial disability or mental illness is a secondary or subsequent impairment

6. Request to Meet

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

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