

Flourish Australia Response to Productivity Commission Position Paper – National Disability Insurance Scheme (NDIS) Costs (June 2017)



Introduction

Flourish Australia welcomes the opportunity to comment on the draft findings and recommendations set out in the Productivity Commission's Position Paper which forms part of its study into NDIS costs. The thorough process being used to undertake the study, including the opportunity for a wide range of stakeholders to provide comment, is appreciated and appropriate, given the complexity of such a landmark Scheme and its importance for vulnerable members of the community.

As a community mental health organisation, our focus is on people with psychosocial disability and how the design and roll out of the Scheme is impacting on their needs and circumstances.

Our comments relate to those elements of the Position Paper that are most relevant to people with psychosocial disability. We have drawn on our 60 plus years of experience providing psychosocial support to people with a lived experience of a mental health issue. More recently this includes three years as a provider operating as part of the Hunter NDIS trial site.

How is the Scheme tracking?

The Position Paper notes that the scale and pace of the NDIS rollout is highly ambitious, that this poses risks, and that some participants, in particular those with psychosocial disability are not fully realising the benefits of the Scheme.

The Position Paper also notes that people with autism and intellectual disability account for almost two thirds of Scheme participants, while people with psychosocial disability account for only 6%. This is considerably lower than the 14% it is estimated will be the proportion of participants with psychosocial disability at full Scheme rollout.

Further, the Position Paper notes that the number of people approaching the Scheme in trial sites that have been operating the longest is higher than would be expected if only people with newly acquired conditions were approaching the Scheme. This accords with our experience in the Hunter where we continue to experience strong demand for, and growth in, the psychosocial supports we are providing under the NDIS.

Flourish Australia believes that this situation relates in part to the complexity and newness of the Scheme, the challenges posed by language that is unfamiliar and can be difficult to understand, and bureaucratic processes that can be hard to access and navigate.

In our experience, people in the Hunter with psychosocial disability are still signing up for the Scheme four years after it commenced, because it is taking time for the realisation that

the Scheme is also for people living with a significant and ongoing mental health issue (who experience psychosocial disability) to take hold.

Feedback received by Flourish Australia from our ongoing involvement in the NDIS and from recent community forums we have held in 2017/18 rollout areas (including rural and remote areas of NSW), suggests that members of the public, people living with a mental health issue and their families, general practitioners and other health professionals, service providers in general, and even Local Area Coordinators and NDIA officers, often do not understand the term 'psychosocial disability', how it relates to mental health, and the fact that it is covered by the Scheme.

This is perhaps not surprising. Until recently, the term 'psychosocial disability' has not been widely used in Australia, although it has been used internationally for over a decade. Many people associate 'disability' with those who experience intellectual, sensory or physical differences, not mental health issues.

Like us, a number of community mental health service providers, advocates and others are doing what they can to overcome this gap in awareness and understanding. Recently, the NSW Mental Health Coordinating Council has worked with people with a lived experience of a mental health issue to co-design a website about psychosocial disability and the NDIS, funded by the NDIA. Initiatives like this are important and will greatly assist in overcoming misunderstanding, confusion and lack of awareness.

However, we would argue that, given the pace of rollout, there is an urgent need for a more concerted effort to ensure that people with psychosocial disability are able to fully benefit from the Scheme. This should include a national community awareness campaign, using multiple channels to target and reach the full range of relevant stakeholders, with the objective to increase understanding of the meaning of psychosocial disability, its relationship to mental health and recovery, and its fit within the NDIS.

Scheme eligibility

Data collection

We support draft Recommendation 3.1 concerning the collection of data on the activity domains outlined in section 24 of the *National Disability Insurance Act 2013* (NDIS Act). This will aid understanding of the nature of demand for support and will potentially guide future planning and development in relation to the Scheme.

Permanency

We accept the Commission's position that it does not support changing the eligibility criteria to relax the definition of permanency and how it relates to psychosocial disability. However, we believe that a comprehensive and well-crafted community awareness campaign (as outlined above) is required to remove the stigma that can be associated with these terms, and highlight what psychosocial disability is, how it can sit alongside and complement recovery models (notwithstanding notions of permanency), and the value of psychosocial support in striving to live an ordinary life.

Without this, there is the risk that the notion of permanency as it pertains to psychosocial disability, and misconceptions in this regard, could serve as a barrier to people accessing the Scheme, and/or to health professionals and others supporting people to access the Scheme.

Our experience highlights that NDIA staff and LACs also need training and guidance in relation to psychosocial disability and its fit within the Scheme. Too often we hear of a reliance on diagnosis to determine eligibility, rather than focusing on functional capacity. We are also aware of NDIA staff forming opinions about whether a person has explored all treatment options and then using this as a determining factor in regard to Scheme access. This is not appropriate.

Health professionals as well would benefit from training and guidance given the important role they play in the access process. When it comes to mental health, health professionals may be well placed to advise on clinical treatment and medical issues. However, some may be less familiar with taking a holistic approach and thinking about how a person's mental health issue impacts on their day to day life and affects their functional capacity.

A person's symptoms may be "managed" by medication, but the long-term impact of their ongoing mental health issue may mean that they lead a very isolated existence, have never held a job, lack social supports and find each day a struggle. If the relevant health professional takes a narrow, clinical view rather than a holistic, long-term one that includes an understanding of the person's lived experience, they could wrongly form the view that the person is being appropriately treated, and that there is no ongoing impact that would benefit from psychosocial support.

Training and guidance are urgently needed to ensure that those who play a 'gatekeeper' role in relation to the Scheme are not effectively shutting out people with psychosocial disability through a lack of understanding and awareness.

Supports and plans

'Reasonable and necessary'

Flourish Australia's view, at this early stage of the rollout, is that the concept of 'reasonable and necessary supports' works well as it is, without being defined by the NDIS Act. It provides flexibility, enables support to be tailored to individual circumstances, and allows scope for innovation. We believe it is appropriate for further clarity to come from court and tribunal decisions over time, rather than needing to provide definitions and further specificity in legislation.

The planning process

We agree with the Commission's view that there is considerable scope to improve transparency and clarity around planning processes. We support draft recommendations 4.1 and 4.2, but provide the below comments highlighting the important role that service providers already play, and should continue to play, in assisting people to prepare for their planning meeting. It is important that this role is appropriately recognised and supported.

We do not support the notion that the NDIA should have the ability to delegate plan approval functions to Local Area Coordinators at this point in time. There is too much variability in terms of skill and understanding across LACs for this to happen. In our view, it would lead to greater inconsistency and poorer planning outcomes.

The role of service providers in pre-planning

Behind the scenes, organisations like Flourish Australia are investing considerable resources and effort to assist people to understand the Scheme, seek access and prepare for their planning meeting.

We understand the need to give people choice and control and to avoid 'client capture' and conflicts of interest. But we are also mindful of our duty to ensure that people with psychosocial disability are able to benefit from the lifelong support and certainty that the NDIS will provide.

Often organisations like Flourish Australia are the main source of support for people living with a psychosocial disability and have been able to establish ongoing, trusting relationships with them. This makes us well placed to support them in understanding and navigating the Scheme, seeking access, preparing for their planning meeting and attending the meeting. The whole process can be confusing and daunting, so being able to go at their pace, support them at each step and provide a consistent presence has been critical in successfully transitioning people into the Scheme.

In relation to pre-planning, we have developed resources specific to psychosocial disability to assist people get ready, we hold regular NDIS workshops and provide one-on-one pre-planning support to people who request it, across our NSW locations. We also draw on the experience of those who have successfully gained access to the Scheme and have gone through the planning process. We provide this support to people already accessing our services and to 'new' people with whom we have been able to connect through outreach activities and community forums. The approach works because of our understanding and expertise in supporting people living with a mental health issue.

We are not funded for our efforts in this regard, but are able to cover costs while identified programs are still transitioning to the NDIS. Once the transition is complete, it will be difficult to continue this important work under a pricing regime that does not recognise pre-planning as a legitimate and necessary activity for service providers to undertake.

We can see that there could be benefits to LACs being in place six months in advance of transition to assist participants with pre-planning (noting that it is too late for this approach for many participants in NSW). However, the role that service providers are playing in relation to pre-planning and the benefits of this for the people we support needs to be formally acknowledged (and appropriately reimbursed) and LACs should be encouraged to take a partnership approach.

Improving the understanding of planners

As already highlighted, in relation to psychosocial disability it is imperative that LACs and planners receive appropriate training, guidance and support in order to improve their

understanding of mental health issues and effectively engage with people with psychosocial disability. As the Position Paper notes, the limited disability knowledge of planners is an issue of real concern. Community mental health organisations would be happy to share their expertise in this regard, as would people with both lived experience of a mental health issue and experience with the NDIS access and planning processes.

The issue of specialised planning teams for people with psychosocial disability has merit and warrants exploration in consultation with people with psychosocial disability, service providers and other experts. As with many processes connected to the NDIS, it is how they are developed and implemented, and the extent to which co-design is employed, that will determine success.

Community mental health organisations have significant expertise in providing psychosocial support and in placing the interests of the person front and centre. Leveraging this and adopting a partnership approach that recognises the important role that service providers play in the planning process would be a major, positive shift.

The NDIS and services outside the Scheme

ILC program

We agree that it is a false economy to have too few resources for ILC activities during the transition period. However, given the aim of the ILC program is to link people who do not qualify for the NDIS to appropriate community and mainstream support, even once fully funded it is difficult to see how the ILC program will be able to rectify years of under resourcing and neglect when it comes to community based support services for people living with mental health issues.

As highlighted by the NSW Mental Health Commission's *Living Well: A Strategic Plan for Mental Health in NSW 2014-2024* (2014) among Australians who experienced a mental illness in the preceding 12 months, only 35% received any formal care; mental health services are harder to find outside of cities; and, in NSW, 54% of the mental health budget is spent on inpatient hospital care rather than community based support, despite the fact that the majority of people who experience a mental health issue will continue to live in the community.

The Position Paper notes the National Mental Health Commission's estimate that about 700,000 Australians experience a severe mental health issue in any one year. It also notes that funding for a number of mental health programs is being withdrawn and 'folded' into the NDIS to offset costs. This stands to worsen the situation described by the NSW Mental Health Commission. It makes it extremely unlikely that the ILC program will be able to meet the needs of people living with mental health issues, as well as others with disabilities, who do not qualify for the NDIS.

The types of projects funded through the ILC to date also raise questions about effectiveness. One-off or short-term grants are unlikely to be sufficient to meet the needs of people who, while not qualifying for the NDIS, can still have complex circumstances and face

significant challenges. Such grants are also unlikely to have much impact when it comes to building the capacity of mainstream services to be more inclusive of people with disabilities.

Our view is that for the ILC program to be effective and achieve its laudable aims, it requires a major rethink and overhaul. As a minimum position, we support the Commission's draft recommendation 5.1 to fully fund the program from the outset and for the effectiveness of the ILC program to be independently reviewed (although leaving this until the next five-yearly review of scheme costs seems too long). We would also add that in the interim, there should be greater transparency about the projects funded through the ILC and the outcomes achieved.

Continuity of support

Continuity of support for those already receiving support and services but who are not eligible for the NDIS is a core commitment that Governments have agreed to. It is unacceptable that, in year 2 of full rollout, there is still no information or detail in relation to what continuity of support means and what it will look like.

People currently receiving psychosocial support from Flourish Australia who are either over 65 or who do not meet the disability requirements for the Scheme are rightly very anxious about their future and are not appeased by vague promises of support continuity that lack detail and specificity. They want clear assurances that they will be able to continue to access the support and services that they currently receive.

Not providing these assurances is causing distress to already vulnerable people. Further, if ongoing support is not going to be available, many Australians who are living with a significant mental health issue but who did not qualify for the NDIS could potentially be left in dire circumstances.

We strongly support the Position Paper's recommendation for Australian, State and Territory Governments to make public their approach to providing continuity of support and the services they intend to provide to people (including the value of supports and the number of people covered), beyond supports provided through the NDIS.

We stress that this is not just a matter for State and Territory Governments. The Australian Government has a long history of providing services to people living with mental health issues and has an ongoing, important leadership role to play in this regard. The sheer number of Australians who will experience a mental health issue in any one year, coupled with historic under funding of community based supports, requires a national approach and continued federal funding alongside state and territory responsibilities.

Provider readiness

Pricing

We strongly support the need for the immediate introduction of an independent price monitor with a view to ultimately transferring the NDIA's price setting power to an independent price regulator by 2019. Tasking the same organisation that manages the Scheme's budget and financial performance with overseeing the process to objectively and transparently set efficient prices potentially gives rise to a conflict of interest.

Integral to the long-term success of the NDIS is the need to get pricing right. Available evidence suggests that a significant number of providers are struggling under the current regime. In the lead-up to deregulation, the price setting process requires specialist expertise, a robust methodology, independence and transparency, and comprehensive consultation with and input from service providers.

Thin markets

The 'one size fits all' approach that characterises implementation of the NDIS fails to recognise the unique challenges in relation to particular locations, such as rural and remote, and particular communities such as Aboriginal and Torres Strait Islander communities (many of whom live in rural and remote areas).

Reimbursement of provider travel

A case in point are the arrangements for reimbursement of provider travel. The 2017/18 NDIS Price Guide sets out that:

'Where a provider travels from one participant appointment to another, up to 20 minutes of time can be claimed against the next appointment at the hourly rate for the relevant support item' (p.14)

In rural and remote areas, it is not uncommon for our staff to travel considerable distances to provide one-on-one support to a person in their home. For example, our service in Bourke provides support to a number of people living in Brewarrina, approximately 100 kilometres away.

Under the NDIS Price Guide we would be able to be reimbursed \$37.26 for a return journey to provide one-on-one support to an NDIS participant in Brewarrina. This compares to \$129.22 for the same journey, if the rate allowed by the Australian Taxation Office for claiming kilometres travelled for business purposes is used (66c per kilometre).

This inadequate pricing model in relation to travel is on top of a unit price for one-on-one support that does not cover costs. It makes provision of this type of support in many rural and remote communities unsustainable, and means that people with psychosocial disability living in these communities are at risk of exclusion from the Scheme.

The 'one size fits all' approach that may work in metropolitan areas will not work in rural and remote areas. A new approach is needed, developed in consultation with people living with mental health issues in these communities and service providers, and including adequate arrangements that recognise and compensate for the real cost of provider travel.

Aboriginal and Torres Strait Islander Communities

Aboriginal people are twice as likely as non-Aboriginal people to experience high or very high levels of distress. They are three times as likely to be hospitalised for intentional self-harm. Further, the suicide rate of Aboriginal people is 1.4 times that of non-Indigenous people in NSW (NSW Mental Health Commission 2014).

The prevalence of disability amongst Aboriginal and Torres Strait Islander people is also significantly higher than for the general population. This is the result of many factors such as poor health care, poor nutrition, exposure to violence and psychological trauma, substance abuse and the breakdown of traditional community structures in some areas.

Despite this, most Aboriginal and Torres Strait Islander people remain at the periphery of the disability service system. The First Peoples Disability Network (FPDN - the peak body representing Aboriginal and Torres Strait Islander people living with disability) has highlighted that this is because many Aboriginal and Torres Strait Islander people are reluctant to identify as people with disability:

'This occurs for a range of reasons including the fact that in traditional languages there are no comparable words for disability. Also, many Aboriginal people with disability are reluctant to take on the label of disability; particularly when they already experience discrimination based on their Aboriginality. In many ways disability is a new conversation in many communities.' (FPDN 2016)

FPDN argues that for positive change to happen in the lives of Aboriginal and Torres Strait Islander people with disability, including the opportunities presented by the NDIS, the change must be driven by the community itself. It also needs to be recognised that this is likely to happen on a timeline that is different to that of the mainstream NDIS. FPDN has called for the establishment of an NDIS expert Working Group on Aboriginal and Torres Strait Islander People with Disability to ensure a partnership approach between Government, the non-government sector and Aboriginal and Torres Strait Islander communities.

We believe a body like this, if given the appropriate remit, resources and time, would be well placed to develop the knowledge, understanding and solutions required to ensure that the needs of Aboriginal and Torres Strait Islander communities are able to be met under the NDIS.

Workforce readiness

Australia's performance in the employment of people with disability is poor. According to ABS data, the participation rate for people with a disability is 53.4% compared to 83.2% for people without a disability. Further, the unemployment rate for people with disability is 10%, considerably higher than that for people without disability at 5.3% (ABS 2016). Compared to other OECD countries, we are ranked 21 out of 29 when it comes to labour force participation rates for people with a disability.

Under the NDIS, the workforce required to deliver supports will need to increase and become more diverse. But as the Position Paper highlights, the workforce is not growing fast enough and we face a potential workforce shortage. Given the under representation of people with a disability in the workforce as outlined above, this is an ideal opportunity to develop strategies that redress this imbalance and meet the NDIS workforce need.

Flourish Australia has been able to leverage the opportunity provided by the NDIS to grow its peer workforce. We give preference to employees with a lived experience in our recruitment processes, and approximately 30% of our front-line staff are peer workers, drawing purposefully on their own experience and recovery journey to support others.

The benefits of peer support are numerous, including reduced rates of hospitalisation, crisis and other service utilisation, better engagement with care, and higher levels of empowerment and hopefulness for recovery (Chinman et al 2014).

We believe that our success in this regard should be replicated nationally. Workforce development policies and strategies that facilitate greater employment of people with disability and address NDIS workforce gaps should be developed as a priority, led by the Australian Government in partnership with State and Territory Governments.

Conclusion

The NDIS is a landmark reform that will benefit thousands of people with a permanent disability who would otherwise face a precarious future characterised by insufficient support, uncertainty and many obstacles to leading an ordinary life.

Under the NDIS people with disability have the opportunity to optimise their independence, fulfil their goals, and exercise choice and control in the process.

The inclusion of psychosocial disability within the remit of the NDIS was an extremely important and positive development. However, certain design elements, the pace of rollout and a lack of awareness that the Scheme caters to those with a severe and ongoing mental health issue, are impacting negatively on outcomes for people with psychosocial disability. As a consequence, the Scheme is not delivering on its value proposition and for many, benefits are yet to be realised.

The Productivity Commission's review is a significant opportunity to identify strategies and solutions to turn this situation around. It will be imperative that actions to improve outcomes for people with psychosocial disability are identified and implemented via a co-design process – that is, in full consultation with people with psychosocial disability, their families, service providers, advocates and others who play an integral role in assisting them to achieve their goals and live an ordinary life.

References

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