

National Disability Insurance Scheme (NDIS) Report from the Productivity Commission-

Individual Feedback.

I appreciate the opportunity to provide feedback to the report and my experience of the NDIS to date. My daughter will be considered for the NDIS in 2018. My sister will be considered by Nov 2017. Supporting both my daughter and sister across Disability Services and Mental Health Services plus currently employing support workers to assist my daughter (through her Individual Support Package (ISP)); have provided me with a view of the landscape to date. In addition, my working life consisted of many years employed in the community and health sectors – youth services, mental health services plus education and training.

The NDIS is a new way of funding supports to enable people to have an ordinary life. The implementation of the NDIS is a unique opportunity to bring about significant social change. This process of education is embedded in all aspects of the NDIS. I have concerns regarding some of the attitudes expressed in the report.

Concern with the presentation of applicants within the report by the Productivity Commission.

The labelling of people as high functioning to low functioning and/or high needs versus low needs continues a culture present in the traditions of poor practice across welfare, health and education. Such language and notions continue a hierarchy of impairment and a view of people in terms of deficits. Most importantly, high functioning or low functioning simply does not communicate the information it needs to. Our language must reflect an understanding of the person's lived experience and the supports needed to have an ordinary life. I believe this should be reflected in the language and culture of all NDIS communication.

Concern with the presentation of 'knowledge and experience' of Planners within the report by the Productivity Commission

The report's statement that some Planners have 'limited disability knowledge' poorly describes the skills and experience required for a Planner to be competent. I note that 'disability knowledge' is described as knowing detail of 'different disabilities' or medical conditions. An understanding of diagnoses is easily accessed in a range of formats from medical sites. However, we know the lived experience is unique and there is a broad range of supports that may meet a group who may share a diagnosis but appear at very different points on a continuum. Surely the Planner needs to have an ability to appreciate and understand the lived experience of the applicant and assist in communicating this within the systems of the NDIS. An ability to navigate the system with the applicant being essential. The report states that a lack of skill in the planner is seen in the variability of packages identified for individuals who appear to have similar support requirements. It is also reported that unexpectedly larger packages were given to some people and unexpectedly smaller packages given to others. This may reflect on the Planner in terms of their lack of

appreciation of the lived experience, their difficulty in navigating the system with the applicant and perhaps a degree of prejudice or disability discrimination, albeit unwittingly, but vulnerability to cultural traditions of a hierarchy of impairment is common if not human. A hierarchy of impairment marks greater social acceptance given to impairment groups. Those higher on the list having more social acceptance and experience less discrimination, using the terms of the NDIS, – those considered to be higher functioning.

The report suggests that Specialist Disability Organisations or Service Providers could be involved in the planning process to meet this gap. I would argue this not be an appropriate strategy nor would it necessarily bring the required skills to the planning role. I believe further thought is required in terms of identifying the essential skills of a planner and then developing appropriate recruiting strategies. There is no doubt the Planner has a pivotal role and continued development of an understanding of the essential skills and 'best fit' is essential. In addition, I do not see a role for Disability Orgs or service providers as intermediaries. I believe this would undermine the scheme.

Concern with how informal carers are referred to within the report by the Productivity Commission

There is reference to informal care arrangements, I assume this refers to employing family or those within a family network, not living with the recipient, to provide support. The report states in the short term these arrangements may need to increase given a prediction of workforce shortages of support workers. It states this must be closely monitored and reduced once the workforce is ready.

- I was disappointed in this as a strategy and likened it to the use of women in the workforce during times of war; displaced and then filled by men after the war. It is in later years we value their contribution and the skills they had.
- It fails to acknowledge the value of informal care
- It fails to see this relationship as a preferred choice for some recipients
- It fails to acknowledge that this can be part of a lifelong relationship
- The care is seen with some suspicion, that is, needs to be watched more closely than other arrangements
- It fails to acknowledge the community education that can result from such relationships
- There is an implication that it is a burdensome undertaking and less satisfactory than others

I think this position needs further consideration.

Report states the scheme differs in that -1. it is person centred care and support; 2. there is a long-term view of cost/benefit (as with Insurance based schemes) and 3. the assessment is needs based.

I agree the scheme should operate under these principles and I welcome it. However, community organisations (Disability service providers et al) adopted similar language for their practice many years ago and have a view and practice around such principles. I believe

the principles have not been well understood. I think there is an inherent challenge in pulling apart preconceived notions of what has been labelled person centred care and support; and needs based assessments. I think this challenge is something that may take decades to evolve. Perhaps new or different terminology to describe these principles could be helpful in the NDIS's pursuit to move away from 'Welfare Culture' -pg. 6)

Media reports of the two cases gone to Administrative and Appeals Tribunals in which decisions made by the NDIS were overturned in favour of the recipient.

In the first case travel support had been denied. In the second case therapist of choice and gym membership of choice had been denied. I was disappointed to hear that the NDIS were seeking to appeal the first case and have not responded to the second.

The NDIS refusal to support, the recipients challenge and the courts' decision is land mark but also good learning for us as a community. It would be disappointing if the NDIS pursued appeals instead of accepting the result that they had displayed poor judgement. All recipients have the right to - not be worse off under the NDIS and to have real person-centred support and care. The tribunals decisions have provided clarity.

The refusal to grant the supports in the first instance demonstrates a 'we know best' approach which marks traditions of welfare culture.

I see this as part of the evolution of the cultural change, referred to previously, that may take decades.

The report states that participant readiness is related to individual capacity, capacity of carers ad peers, assistance under the NDIS, readiness of the market place and complexity of the scheme.

An individual's capacity is supported by being well informed. I observe there are many forums for service providers – 'meetings upon meetings' I hear said. Service providers and the NDIS have created opportunities in which it seems family members and those identifying as carers, being the target group. I observe this particularly in relation to the group described as have a psychosocial disability or a mental health diagnosis. I have heard a range of statements from those who work in service provision and advocacy regarding providing information to applicants.

'imagine confused people making decisions about their care, it's not possible'

'we haven't decided what information to give them yet'

'and who is funded to do that?'

'I am still waiting to hear information to do with our service and how we administer it'

I was interested to read in the report that it is this group, described as having psychosocial disability, that have demonstrated poorer outcomes and less success in navigating the system.

The implementation of the NDIS has caused considerable confusion and instability from service providers. It seems to me that there has been a lot of time spent concerned about how to maintain the status quo and one's patch, understandably, instead of taking up the role of supporting applicants through the process. The scheme has the potential to change the social order and if recipients have real choice and control then service providers are more accountable to the person they support. This is a significant change for people who have built careers in which they have made major decisions about the delivery of services. Again, I think this shift will take decades.

We will learn a lot about what are the key ingredients to support through this process of social change. It will better inform the community in terms of the supports required by people who do not meet the NDIS, yet require assistance.

Concerns expressed in the report – the roll out schedule may be too ambitious, market and provider readiness, NDIA capacity of the systems and quality of the plans.

Development of the ILC, market readiness and quality planning are crucial to success of the NDIS. For me who awaits the scheme for 2 people I support, slowing down the process to improve the systems could be a welcomed and considered option.

Market Readiness is a concern for the NDIS

A shortage of competent workers is predicted in the short term. This may be reduced by implementing strategies as suggested by the report – experienced workers increasing their hours, informal care arrangements to increase and skilled migration. My concern with skilled migration is that people may be encouraged to work in a field where there are jobs as opposed to having the disposition for it. Cultural values toward disability can vary with some being at odds with those required to be an effective support person. A good match of cultural values and language is an essential part of the relationship between recipient and worker.

A factor that can appear as a shortfall in the workforce can be a difficulty to locate a support worker. Networks that enable recipients to connect with support workers with common interests is vital and in need of development. 'Hire Up' being a good example of an organisation trying to meet that gap.

Another strategy would be to promote support work to students engaged in studies of health, education and community work. This would provide valued employment to students, provide opportunities to increase their skill set, have long term benefit when they are employed as professionals plus attract younger support workers to the market. Students may commit to work for the period of their studies which would challenge the current casualisation of the workforce.

Striking the right balance in terms of regulation/control of costs of supports identified in the report suggests 3 stages – independent price monitor, regulation and ongoing watch. Control of costs would seem a vital mechanism but any regulation would need to be independent with the ability to respond to poor practice. Regulation without any power would enable another toothless tiger to disappoint its community.

I appreciate the opportunity to respond to the report

Regards

Jenny Harrison