

I am writing this response as a person with disability who is hoping to receive assistance through the NDIS after 1 July 2017. I am 45 years old, have a lifelong disability and I have been wheelchair-reliant for over 20 years. I have no cognitive dysfunction, no diagnosis and I did not receive any recognition or support for my obvious physical challenges as a child. I know that I am unusual for a person with disability; I live independently and have the good fortune of having the support of a family with the energy, ability and financial means [through hard work] to enable my education and subsequent full time work in a role that touches on disability services in NSW. Despite my knowledge and ability to navigate the current disability service system, it helps me very little, due to its inflexibility and focus on young people with intellectual disability,

I am thrilled about the individual focus of the NDIS, and the flexibility and consumer empowerment it offers, but **I am concerned that this NDIS Costs study has been initiated by people who do not appreciate what the NDIS means for someone like me, and its objectives to improve the lives of individuals and Australia as a community and an economy.** The potential of so many people with disability is currently unrealised and the life journeys of individuals like me, and our families, are tougher than they should be; lives are often incomplete and unsatisfying. As I often say to my friends, "I can do anything, I just can't do everything"; without assistance for my physical disability, I have had to make choices about how best to use my limited energy. I have chosen to educate and work and, because my needs don't neatly fit in the inflexible slots of current service types and hours of operation, I spend two hours each morning getting ready, spend a large proportion of my income on taxi transport and have little energy outside the working week for a personal life. I'm currently a productive member of the workforce, a taxpayer and a consumer [what the government wants], but I don't know how much longer I can do this without formal supports, as my parents are now ageing. Whilst I love my work and find it very satisfying, I don't have what my able-bodied friends enjoy in their non-work time; I don't have a partner [no energy for dating], I don't go on holidays [no one to go with and private support workers are too expensive] and I don't/won't have a family of my own [not necessarily my choice].

I truly believe my life would have been better with an NDIS in place, with more choices and opportunities [including higher paying jobs], and I wish that for my younger peers with disability. I have faith in the Australian Productivity Commission to do this NDIS Costs study; however, there are so many questions, many of them too premature to be asked in regard to a new program, and so little time to respond; I fear that the Productivity Commission will not get the breadth and depth of responses as their last inquiry into disability care and support. **I worry that those who do not understand NDIS will then make changes to the Scheme, which will cut it down before we have the chance to see what it can do.** Indeed, NDIS hasn't even rolled out in areas such as the one in which I live, so how can we answer many of the questions posed in the paper?

I can only tell you how NDIS affects me today and my hopes for the future...

- I can't wait to talk to a Planner about what supports I need and discuss my life goals, rather than a provider trying to define me by my disability and telling me what they offer. I know I am advantaged by my confidence and ability to self-inform and self-advocate, and I understand for some people this is a huge, scary change that they are delaying embarking on.
- I don't think I will have trouble utilising my plan, because I am overdue some support and will fully appreciate the value of NDIS funding. I've done my research and I know what's available in my area; however, I appreciate that I live in a city area where there is choice of providers and my needs will not be difficult for me to articulate and negotiate around.
- I plan to self-manage, so my choices will not be limited to registered providers or the Price Guide, which I think contains some very unrealistic cost limits that do not reflect the true price of flexible, quality services. I appreciate that I am fortunate to have the skills and family to help me with budget control and decision-making, and my professional background has given me a realistic understanding of the costs of providing services, including organisational operations, staff training etc.
- I believe that it is appropriate for NDIS to fund reasonable and necessary costs of care and support associated with permanent disability, because these are the costs of living that a non-disabled person does not have to re-direct their time, energy and income, or that of their parents, towards. NDIS will give people with disability the opportunities for education, career development and life generally which are on par with the rest of the community. Then, we all pay for our own food, accommodation, clothing and leisure with our incomes/pensions.
- I think that it is appropriate for NDIS eligibility to be for under 65s, because this is the work-productive period of life in which the insurance scheme aims to benefit Australia. However, for these first ten years of implementation, I believe NDIS should also assist older people with a lifelong disability, who have spent money on expenses related to their disabilities and/or have not been able to work sufficiently during their productive years to accrue assets and generate savings for old age, as non-disabled people do. Also, aged care may not meet their disability needs; people like me will enter NDIS and not exit, for that reason.

- I don't think that social support or leisure costs or fees should be provided by NDIS funding. I believe that inappropriate funding of all-expenses-paid holidays, sport and recreation for young people in the current system has directed money away from core care services for people with physical disability, communication aids etc to enable people to educate, work and function generally. Of course, it is appropriate that the NDIS can provide a support worker to enable involvement in mainstream leisure activities.
- I wish my parents and I had benefited from early intervention services; we wasted so much time, money and stress when I was a child seeking a diagnosis, instead of focusing on the practicalities of daily life. Things could have gone much better for me in life if we had been helped from the start, and had that happened, I may not have required the level of supports that I need today.
- **I am hoping that NDIS will affect positive change in community attitudes and responsiveness to disability, and enable Australians to recognise that individuals are equally valuable, despite differences in ability.** My experiences in the Health system, for instance, have been of disrespect, inflexibility and ultimately a failure to provide useful advice or help to enable everyday living. Indeed, what sort of 'service' is the health system when my friend with Downs Syndrome was denied rehab after a stroke because, it was reasoned, she was disabled to begin with?!
- I am fearful that ILC will not meet its objectives, due to insufficient funds and the short-term nature of allocations. ILC is, to my mind, an essential component of the NDIS, for information, participant education and for the development of the disability service market and community overall. In NSW, it will be particularly important, because there will be no funded supports available for people who do not receive an NDIS package. As an experienced community developer, I know that creating and stabilising a trusted information service, sustaining a community presence and affecting social change takes more than a year or two.
- I am confident that the NDIS planning process will recognise that my 'disability' is a social construct and that a medical diagnosis is irrelevant to my day-to-day life. Ongoing funding for work-related travel and practical help, together with occasional allocations for equipment purchases, when and how I need them, will allow my ongoing contribution to the world and some enjoyment in living. I also look forward to not having to rely on my tired mum and dad so much.
- I hope to receive sufficient funds to employ workers who meet my personal needs and standards – good, respectful and sensible people, who are willing and able to assist as I require – and I want to be able to pay them at an appropriate level, which reflects how important they are in my life [and how important my life is in Australian society].
- **I hope that the NDIS will remain in place and operate as an insurance scheme over the long-term, as it was planned by visionaries who were committed to achieving a better future for all Australians**, not just winning the next election.