



# **The National Disability Insurance Scheme**

Looking back to see the future

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Looking back to see the future

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**By** 2019, the National Disability Insurance Scheme (NDIS) will offer people with significant disability in Australia a measure of entitlement to support, greater choice and control in the delivery of that support, the prospect of much more personalised options and lifestyles and relatively easy portability of service resources across the country.

Some suggest that people with disability have not seen change of this magnitude since the Disability Services Act in 1986, which sought the participation and inclusion of people with disability in community life. Regardless, reforms of this kind are long overdue. The former National People with Disabilities and Carer Council's Shut-Out Report in 2009 claimed people with disability were “excluded and ignored” in a system that was “broke and broken”.

In 2013, the Australian public massively supported a new system that would cost them an additional levy. In return, they expected people with disability to be given the ‘fair go’ they were due, and a chance to participate socially and financially in community life. The public now expects this change to be relatively swift and seamless.

Very early in the process some people with disability will likely make prompt decisions about their lives and not look back. The experience of the last thirty years, however, suggests much more long-term developmental challenges lie ahead. Change of this magnitude cannot be expected to be swift or easy. Looking back on past reforms offers some lessons that predict future challenges for the NDIS.

Traditional services will find change difficult

**S**elf-directed individualised arrangements espoused by the NDIS have been around for some time to varying degrees

across Australia. The change agents in the past who pioneered them were often people with disability themselves, their families and allies as well as some state governments who saw the need for this service approach to evolve. The larger traditional services as well as many equally conventional smaller ones up to the present can be remembered for their reluctance to change their existing practices and models in favour of people directing their own support. Their significant investment in property, fixed service models and increasingly corporate organisational structures gave considerable control and dominance to these traditional services and many people with disability and their families preferred their perceived reliability to the uncertainty of change. It can be expected that these traditional services will again make a convincing case that their clientele should stay in these same arrangements, and many people will—for the time being.

The plausibly realistic hope is for incremental change in the number of people electing to create highly individualised and self directed options as more and more people determine the direction of their own lives. This possible transformation will vary from State to State. Western Australia has supported families and people with disability to self-direct for decades, and the practice is now well established. In contrast, New South Wales has only recently gained a small measure of such experience, and it undoubtedly will be harder for many services to fundamentally change.

### Entitlement will not be absolute

**T**he NDIS was launched on a theme of service security and entitlement, and many people may consider this will be an entitlement in absolute terms. The past suggests this will not be the case. Reforms for greater equity and inclusion for people with disability have been consistently under-

funded for decades, and although the Government has given priority to people with disability recently, this attention is unlikely to last. Further, governments cannot give absolute guarantees of financial resources. All systems have limitations, and as Australia heads into an uncertain economic future, the NDIS will not be immune.

People with disability will take time to build capacity

**P**eople also speak of “choice and control” as an absolute —you either have these or you do not. Choice and control are on a continuum, and a continuum in different dimensions in life. In this sense, choice and control are always going to be issues to be negotiated to some degree. Previous service arrangements in the past gave people with disability little capacity to direct their own lives. The NDIS does offer people with disability and families the opportunity to build capacity to negotiate more options; however, it will be an ongoing challenge, rather than a settled matter. Individual funding and self-direction are not panaceas and there are many challenges involved in making life better. Hence, the question of what other supports may strengthen their hand needs to be more carefully examined.

Funding will not buy a good life

**I**t is also suggested that, if people with disability and families are given the authority, they will know what they want out of life and services will inevitably do their bidding. Funding doesn't automatically make a good life for people nor does it invariably make lifestyle development and services creative. Both people with disability and services will need courage and help to be creative and to imagine and pursue a better life. Being creative means struggle, discomfort, and doing something different with many errors and setbacks.

In the past, it was hard for services to change and the bigger the service, the harder it proved to be. The impetus for change to this point has largely come from smaller initiatives that worked in partnership with people with disability and their families. It will be hard to bring that kind of quality to scale without additional support for competent community-led capacity development as part of the normal ongoing strategy of the NDIS.

Again, it can be expected that pockets of change will pop up here and there where leaders relish the discomfort and the opportunity to be creative. The change will need to be ground-up and driven by these leaders, small agencies and possible deliberate agency transformations—rather than a top-down prescription for the service system by technocrats lacking experience with what is involved in assuring quality outcomes “one person at a time”. The NDIS will be wise to build the capacity of these “bottom up” leaders—people with disability, families and their allies—as agents of change.

It will be critical to start and stay with the person

**O**ur past service system identified some people as “difficult to serve”. When people are put in the wrong setting with the wrong support at the wrong time, there will be difficulties. The NDIS offers a great opportunity to serve people better, to start with the person, to get the support right and to tailor that support over time. The better an individual pattern of support fits the person, the better the outcomes.

Many programs in the past have begun with a high level of flexibility and, over time, the rules tend to accumulate to form standardised solutions. NDIS will do well to learn from this lesson. It will need to safeguard flexibility and negotia-

bility if practices are to stay focused on the person, and not to fall into the trap of using individual funding to purchase prescribed “same-old” service solutions.

Life is more than services: People with disabilities need friends and allies

**In** spite of the rhetoric of inclusion and participation in past programs, many people have ended up with little more than segregated custodial care. Not enough attention has gone into focusing on the person having a good life. The NDIS will need to address the fundamental tension between the life goals of a person and custodial outcomes and preoccupations of services. One answer is the rightful and critical presence of natural supporters, people with freely-given connections and relationships with the person. If the NDIS overlooks these, it will potentially subjugate a person’s life to a reliance solely on money and bureaucracy, and deny them the hearts, minds and gifts of ordinary people in the community. Further, it will have betrayed the current public interest in people with disability contributing to society, having a good life and getting a fair go.

Need for ongoing advocacy

**It** would be naïve to portray the NDIS, formal services and much of the generic resources of communities as necessarily always being faithful to people with disability and their families. Indeed, a more realistic view would be to see them as part of the problem of why life has been so hard for people with disability. Indeed, many reforms in the past have resulted from people with disability and their allies speaking out through funded advocacy support. One needs to ask who will support people with disability in the future to challenge these powerful interests when they do not get it right. Part of the “fair go” moral mandate from the public to

the NDIS is to ensure that people with disability are treated fairly and they have the means to make their case.

The NDIS will not ensure an immediate change within the disability sector to self-direction for people with disability and greater choice and control over their lives. Rather, it is more likely to happen incrementally over time. People with disability, their families and their allies will continue to lead the change in small pockets of creativity across the Nation out of necessity because they cannot count on others to do this. The past thirty years are full of lessons of how programs with lofty ideals can lose their way. The NDIS must learn those lessons and people with disability, families and their allies must do their best to shape the NDIS to be their own. None of this will be easy, but great encouragement can come from seeing what has nevertheless been accomplished prior to the NDIS and it is exactly that kind of leadership that will shape its future.

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## **ABOUT THE AUTHORS**

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