

SUBMISSION TO THE PRODUCTIVITY COMMISSION  
ON THE REVIEW OF THE NATIONAL DISABILITY INSURANCE SCHEME [NDIS]

## 1. INTRODUCTION

The NDIS aims to give people with a disability the power to exercise choice and control over the support and services they receive in order to improve their wellbeing and that of their families and carers, provide better options for education, employment, better living and community participation, and to provide efficiency gains plus cost savings to disability support and to other government services.

This wide and valorous statement has generated huge good will and expectation within the community without attempting to describe how the practical difficulties associated with identifying or defining the issues involved, and the administrative and financial arrangements necessary are to be identified, agreed and implemented. A formal arrangement has been devised between Commonwealth and States to introduce and finance the NDIS. What seems to have been overlooked in all the enthusiasm is that the aims, which are basically aspirational, are being touted as practical objectives. My view is that the aims are too broad and ill-defined to be successfully realised and therefore, are not just misleading but inhibit the full introduction of the NDIS by raising expectations to an unrealistic level.

The present situation is reminiscent of an earlier exercise when people assigned to institutions around the country were deinstitutionalised. The well-intentioned policy was disastrous because, despite Commonwealth/State agreement, the States saw it as a cost cutting exercise whereas the proponents of deinstitutionalisation thought its ultimate success depended on extra funds being provided. The NDIS boasting good intentions but with ill-defined and probably inconsistent aims invites a similar result.

Given the existing funding arrangements for the NDIS and the present reaction of State governments [I have had personal experience of the ACT government during the recent ACT trial], I think it likely that the State and Territory governments see the exercise as one where the States and Territories reduce their financial commitments as the Commonwealth assumes greater financial responsibility for the roll-out and management of the Scheme. Ironically perhaps, the States and Territories are responsible for much of the legal umbrella under which the NDIS is to operate. This is especially so for the administration of the Scheme by care providers.

## 2. BACKGROUND

My name is Michael Boyle. I am 79 years old and have a son diagnosed with a 'minor intellectual disability' and Asperger's Syndrome [now included within the autism diagnosis]. My son lives independently, works part-time and is self-managing in many respects. The combination of the intellectual disability and Asperger's means that he does not relate well to people he does not like, and experiences difficulty in making decisions and organising and managing important aspects of his life. Early physical difficulties such as strabismus and fine

motor movement largely have been overcome. He is receiving assistance from the NDIS, a disability tenancy support association and a disability employment agency. In primary school and in college he attended special education classes. Throughout his life he has been supported by family and friends who have helped enormously with his wellbeing and in assisting him come to terms with his disability.

My wife and I are his primary 'carers', providing family and other support; however we are getting old and like thousands of other parents in a similar situation we are thinking about what should be done when we are no longer able to help.

Many look to the NDIS for ongoing reliable, secure and stable assistance to fill the gap made by parental departure regardless of the continuing support from family and friends. From my experience of the NDIS/NDIA operation, I think this expectation is too optimistic. Formal guardianship may be a solution, but the best guardian is often a friend or family member and that depends upon availability and willingness to get involved to the extent necessary. The bigger question is whether arrangements made through NDIA are intended to replace or substitute for the 'care' provided by parents and, if so, to what extent?

As part of my support for my son I have been a member at various times of several community organisations: DADA [Disabled and Disadvantaged in the Arts]; Sailability, sailing for those with a disability, and Capital Community Housing [CCH], specialising in tenancy management for those with a disability. DADA and CCH no longer exist. The ACT government withdrew funding from DADA, while CCH was not accepted as providing a service within the NDIA prescription.

### 3. ACCOMMODATION

It is obvious that NDIA provides services to people who have accommodation either in public housing [shared or single] with parents or relatives or privately owned or rented. Realistically, it is difficult to see how the NDIA could fund homeless people with disabilities so that they may employ care providers while still being homeless. Even those who may be living in homeless shelters which are normally temporary accommodation and the arrangements do not lend themselves to proper care provision.

Social housing providers are quick to point out that where special arrangements have been made for housing people with a disability, there are many living in general social or public housing who have disabilities covering the whole gamut of mental, physical and intellectual problems. As individuals, these people can access the NDIS although the physical circumstances of their lack of permanent accommodation make the delivery of some support services difficult and uncertain. Social housing availability however, is well behind meeting the demand.

The NDIS has announced that \$700 million a year would be made available as a fund to seed the development of solutions for disability housing. Details are lacking and no indication has been given that the ramifications of the problems involved are understood – possibly because housing is a State rather than a Commonwealth function. The basic idea is that the initiative for housing should be taken up by private developers and entrepreneurs rather

than State governments whose responsibility for the provision of social housing including disability housing will continue. The involvement of private enterprise is an attractive proposition because the costs of building are thought lower, but this ignores the underlying requirement that developers and entrepreneurs are in business to make a significant profit. It might be that the bureaucratic cost of government social housing is so expensive that even with a substantial profit margin, private developers produce a better and cheaper product?

My strong impression is that the States and Territories are working to unload commitments wherever they can by selling stock to private and community organisations, and through encouraging but not necessarily subsidising, private enterprise to build and manage for profit disability accommodation. While some Commonwealth housing initiatives work well, such as Commonwealth Rent Assistance, others such as the affordable housing scheme do not. The point is that the demand for social housing far exceeds its availability. The corollary is that everyone receiving NDIS support must be appropriately housed.

The recent history of Capital Community Housing [CCH] is a case in point. CCH operated for nearly 40 years and developed into a community housing organisation specialising in disability tenancy management. At the time of its dissolution it managed over 100 properties with around 200 tenants, some in shared accommodation, others in specially constructed or stand-alone accommodation spread throughout the general community. The turnover was in excess of \$1 million and six permanent and several part-time staff were employed with occasional assistance from volunteers.

Funded originally by the ACT government, with the largest rent coming from Disability ACT, the introduction of the NDIS saw the ACT government give the money previously directed to CCH to NDIS. Transition funding was provided while CCH moved under the NDIA umbrella. The NDIA rightly decided that tenancy management, or whoever controlled the accommodation, should not provide care as that would give rise to potential conflict of interest by having the tenant dependent upon the same agency for housing and care. NDIA ceased funding CCH on the grounds that it was a tenancy agency and not a care providing body. Unable to find alternative sources of funding, CCH ceased trading. Its former tenants and assets were transferred to another community housing provider where it is hoped that its existing administrative support services will absorb the management of CCH tenants without additional cost but gain from the additional CRA. If this does not work out then that community housing agency probably will suffer the same fate as CCH.

The problem with the NDIA decision while apparently right in principle, made no allowance for the fact that tenancy management for people with a disability requires a flexibility of approach and activity not expected of a mainstream real estate agency. Just the act of explaining the responsibilities of a lease for lessees and lessor to a person with intellectual difficulties may take a long time, and have to be repeated every time there is an issue.

A similar situation may occur in dealing with all the other aspects of tenancy management plus discussions with carers and guardians including negotiation and conciliation of emerging problems in shared accommodation.

The grant from the ACT government could be managed to cover these costs, the NDIA saw them as a matter for a carer. Unfortunately, because the 'fees' estimated were low, the circumstances variable and the administrative effort considerable, CCH was not aware of any care provider willing to step into the breach.

The fundamental issues are:

- a. Successful implementation of NDIS services depends, among other issues, on the recipient's enjoying secure, safe, stable and appropriate accommodation. The problem is that not everyone deserving NDIS assistance will have such accommodation.
- b. The provision of effective and efficient care under the NDIS is not just budgeting for the services but the way they are delivered in a manner recognised, understood and appreciated by the recipient. Within practical limitations the delivery of services must be consistent.
- c. In delivering those services flexibility is essential, because many in the disability community have disabilities inhibiting their exploitation and enjoyment of those services. They can become confused and disillusioned by changes they do not comprehend.
- d. Budgets must be accounted for to prevent negligence, fraud and theft, but the system devised needs to recognise what is involved in service delivery. This means acknowledging that the substance, means and manner of service delivery is strongly influenced by the nature of the disabilities being serviced. For example, many people with physical disabilities unaffected by intellectual problems can function either normally or with largely physical support. They do much to help themselves. Those people with intellectual difficulties need sympathetic assistance even in understanding what is involved in the NDIS services designed to assist them. Where physical and intellectual disabilities are combined it is even more complex. Add mental illness to the mix and the problems may increase exponentially.

#### 4. COORDINATION AND LINKAGES IN DISABILITY SUPPORT

The NDIS was not intended to embrace all disability programs. Many people within the disability community are aware that there is not only an interface between these programs at the individual level, but an inter-relationship and in some cases, dependency, for example the starting of a program may depend upon the completion of another.

Partial recognition has been given to this fact by encouraging those with several care providers to engage a coordinator to coordinate the program and its funding. More work in this area is a necessity where the programs to be coordinated are outside the main focus of the NDIS such as health, accommodation and education. The NDIS will budget for access to those programs [whatever that means] but the programs often is funded by State and Territory authorities, meaning that the role of coordinator is limited.

The question arises whether the current approach to coordination is sufficient or whether in the interest of cost and efficiency it should be extended to cover a participant's involvement in all programs, State and Commonwealth.

## 5. CARER ORGANISATIONS AND THEIR STAFFING

Until the advent of the NDIA most carer organisations functioned as non-government agencies operating within the community. Funded largely by government grants, donations and limited fund raising activities, their staff usually met the first requirement for working successfully with the disability community. They genuinely liked working with people who had a disability and this is the first requirement. Their motivation was not based on sentiment, sense of duty or a desire to make money. Their reward was knowing they were helping people who might not otherwise be able to help themselves. Other qualities needed to help are patience, tolerance, common sense and a sense of humour. Technical or clinical knowledge is relevant in specialised areas but is not a universal prerequisite. The essence of community work is the ability to win the confidence of the client by achieving successful communication and trust.

The introduction of the NDIA supplants the volunteer and forces many NGOs to become commercial business enterprises that must make a profit to survive. It is only necessary to recall the problems and scandal that have beset the nursing home industry to be reminded of the difficulties that arise when initiative is surrendered to unconstrained private enterprise and market forces. Twenty-two billion dollars a year is an incentive for fraud and theft with an irresistible gravitational pull for every con-man and fraudster hoping to make a quick buck. Those people self-managing are most at risk if they are inexperienced in managing money budgets.

The NDIA publishes a list of registered care providers. The NDIA refuses, however, to provide an assessment of the professional competence and reliability of those organisations. Given the implication for clients and the providers as well as accountability for the expenditure of NDIA funding, can the NDIA afford not to undertake such an appreciation especially if the drive for efficiency and effectiveness are NDIA priorities? Not to mention any residual responsibility the government has to protect vulnerable clients from fraud, theft and other abuse.

Several community organisations have been wound-up in the ACT since the introduction of the NDIA. As the scheme rolls out this will be repeated across the country. Financial pressure will bring about mergers and, in some cases, this will promote cost savings and efficiencies of scale. Large organisations, however, are no guarantee of improved service – some of us would point to Telcos and banks as examples in this regard.

A major difficulty facing the NDIS and NDIA is that despite high-level consultations between some parties, trial implementation areas and reviews, no-one is positive about the full range of activities and assistance to be funded by the NDIS.

So far as I am aware the States and Commonwealth have not researched the scope of injuries, disabilities, disorders and illnesses that give rise to disabilities. Similarly, no

'stocktake' of the services to be provided, where and how often, has been completed. The lack of firm and agreed definitions and diagnoses may contribute to the problem allied with the inability to equate those definitions to the amount of care to be provided and the professional quality of organisations already in the field.

The NDIA appears not to have a reliable estimate of future costs including the number of people who can be anticipated to claim assistance over, say the next 25 years. For example, drug addiction is a continuing problem. Surely research has been done on the extent to which prolonged addiction causes intellectual, physical and mental disability. Therefore, it should be possible to estimate the number of former and current drug users likely to require NDIS assistance. The insurance industry may be able to assess the ballpark figures for home, industrial and traffic injuries that fall outside the parameters of insurance compensation.

## 6. FUNDING THE NDIS/NDIA

The public is increasingly aware that the full rollout of the NDIS is seriously underfunded. Including an NDIS levy with the Medicare levy payment is a mistake for the Medicare levy needs to be adjusted to cover Medicare costs [e.g. the expanding Medicare gap] while the NDIS portion of the levy will require constant upwards adjustment unless an alternative source of funding is identified. Even though the bulk of the electorate might be sympathetic to NDIS aims, they would be exasperated by double bites possibly without the benefit of transparency. Public reaction to rising NDIS costs will be influenced by their reaction to rises in rents, rates, taxes and the cost of living generally, school fees and health costs unless wages are more than compensating for those rises plus inflation. It seems that the States may have been more alert to the consequences of rising NDIS costs than the Commonwealth.

Given the present state of the economy and difficulties with Commonwealth tax revenue there does not seem to be a convenient remedy. The following factors also will add to the rising costs burden:

- a. The cost structure for services provided by care organisations will rise annually and outdistance the charges set by the NDIA.
- b. The increasing cost of labour together with an inevitable demand for improved services, training and qualifications of staff will be reflected in overall costs.
- c. An increase in management and administrative costs, especially when government/NDIA impose additional regulatory and/or statutory requirements.

Community social workers operating in the field tend to be dedicated and frequently underpaid because of a willingness to work longer where a client needs extra assistance. It is already clear that the effectiveness of the NDIA/NDIS depends upon the willing cooperation of family, guardians and fiends. This voluntary commitment is not capable of being assessed in terms of monetary compensation. The extent that the people remain available to continue this commitment is unknown, although anticipated to continue at a high level.

The NDIA [and governments] are relying on the discipline of the commercial market and innovative, entrepreneurial management to solve those problems existing under the government sponsored and subsidised system. This reliance may be justified in some cases, but it depends on a profitable return for the business over and above operational costs. This profit depends on the amount the NDIA is prepared to pay for the service. No profit, no business, is the principle. Does this mean that governments will need to pick up the shortfall in the overall operation of the scheme if insufficient funds are available to sustain what many regard as an artificial market? Possibly there are lessons for the NDIS/NDIA flowing from government experience in the energy market where allegations exist that the government subsidy of renewable energy distorts market processes. Although not-for-profit agencies function on a non-profit basis, they still must earn enough to meet ongoing increases in staff, resources and administrative costs.

## 8. EMPLOYMENT

There is no reliable estimate of the numbers of people necessary to staff the care providers, but as old organisations dissolve or merge there is no guarantee that staff will transfer over or stay within the industry. In the case of CCH at least half the staff were adamant that they were leaving the industry for good. There will be staff turnover and not all recruited staff will be suitable to work face to face or manage those with serious disabilities especially intellectual disabilities. Problems are apparent already where providers rely on temporary or part-time staff and where the demand for services exceeds the capacity to supply them. The problem can be exacerbated where the client decided to change or reject the care provider. The Productivity Commission's argument that the NDIS would create vast opportunities for employment is true only if the right people are employed who can function within the envelope of responsibilities.

Employment for those with a disability depends upon the nature of the disability and the availability of suitable employment. The Productivity Commission does not argue for the NDIS to operate as manager of employment services. Employment opportunities for people with a disability are very limited especially for those with intellectual limitations. The projected introduction of robotics and artificial intelligence may well see existing opportunities diminish further.

Work is important to the health and wellbeing of everyone but especially to those who are ill or have a disability and suffer consequent lack of self-esteem or possess limited opportunities for socialisation. Work helps in dealing with isolation and depression which add to the problems and difficulties of those with a disability and may be reflected in demands for further NDIS assistance. The NDIA may be dismissive of my submission possibly arguing that the NDIA/NDIS function is to act like an insurance agency making payments to deserving people, but having little if any responsibility for how well that money is spent by the individual. In a different world this might even seem a plausible argument, but it is irrelevant where twenty-two billion dollars of government/taxpayer money is being spent on approximately half a million disadvantaged Australians.

## 9. WHAT IF WE COULD GO BACK TO THE BEGINNING?

The NDIS suffers from too many aims accorded equal emphasis. It appears unable to estimate costs and establish the extent and complexity of service demands. Many suspect that it suffers from inadequate knowledge and experience of the disability community so that its judgments and policy are incomplete through insufficient information upon which to base them. Existing Commonwealth State funding agreements seem insufficient for the NDIS to meet its agreed responsibilities. Within the electorate expectations for the NDIS may be unrealistically high.

A few years ago in Beechworth while I was discussing the NDIS with a businesswoman and mother of a seriously disabled child, she made it emphatically clear to me that after years of effort she had finally got from the Victorian government a package perfect for her child's needs and future. Nothing would convince her to give it up regardless of any proposal to do with the NDIS. To her the NDIS could have been an aberration. I am in complete sympathy with her position, yet the impact of the introduction of the NDIS in Victoria very likely will create further unnecessary turbulence in her and her daughter's life.

It may have been preferable, with hindsight, to have identified and retained those successful disability programs run by the States and Territories with the Commonwealth offering to fund improvements, provide Australia-wide information and assist with the design, implementation and coordination of programs intended to fill identified gaps or improve existing programs. Perhaps this is what the Western Australian model is intended to do?

It is possible that over time after the initial requirements of the NDIS are rolled out that the demand for services will lessen and costs diminish. It is also possible that new pressures will emerge. When the NDIS was first announced approving comment was made about similar schemes in NZ, the UK and, I think, Sweden. I can see no comparison because each has a central government and none share Australia's distance and resource problems. After all it took 100 years for the States to agree on a standard rail gauge! The success of the NDIS depends heavily on Commonwealth/State cooperation even though the money comes from the same source ultimately, the Australian taxpayer.

## 10. CONCLUSIONS

The NDIS has been run-out too quickly with insufficient consideration of not only what was to be achieved, but what resources useful to the exercise were already available in the states and where were the most difficult and pressing issues. Commonwealth political ambition permitted the States to avoid a reasonably apportioned share of financial responsibility. Haphazardly planned test programs appear uncoordinated and of limited value in rolling out the full scheme. Public expectation has billowed although some disillusionment is increasingly apparent and probably will grow as the scheme's limitations become more obvious.



My hope is that the present review will publicly address the problems and circumstances that currently exist and help bring about a better appreciation of what is and what is not possible, what objectives are realistic and what is aspirational and perhaps being capable of being met at a later time. Failure to achieve this could see the NDIS joining Gonski and the Pink Batts schemes as examples of how not to govern for the benefit of the people.

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