carers alliance
making the personal political

National Disability Insurance Scheme (NDIS) Legislation – Submission Submission

About us

Carers Alliance was formed by carer-families as a political arm to carer-family lobbying. Carers Alliance aims to bring public focus on the issues associated with lifelong care and to ensure that the people who we care for, and care about, are provided with the supports they need to live full and engaging lives.

In submissions to countless government inquiries, carer-families have consistently called for a responsive, adequately-funded service system that delivers person-centred population-based benchmarks for funding. The calls were made by carer-families long before the Productivity Commission (PC) first considered a lifetime care and support scheme, which is now the National Disability Insurance Scheme (NDIS, the Scheme) and long before the Shut Out report was released in August, 2009.

It was carer-families who were out in the public domain exposing the shameful neglect of people with disabilities by successive governments. Carer-families took their campaigns to parliaments around the nation; and via television and radio into Australian living rooms; exposing the chronic state of neglect of people with disabilities. Without mincing words, it has been carer-families who have been the conscience of the nation, calling neglect for what it is and condemning rather than praising the pittances and platitudes offered by politicians and bureaucrats in lieu of real funding during state/commonwealth negotiations.

Carers Alliance has high hopes that the NDIS will support all people with significant disability in such a way that ensures real inclusion into the broader community. We commend the Commonwealth government's commitment to an NDIS on behalf of the Australian people and for committing to at least the sharing of the cost of care with the states and territories which have been overwhelmed by the task for decades. Ideally, like the PC, Carers Alliance would have preferred that the NDIS belonged to one level of government rather than all levels, given the historical jurisdictional blame and cost-shifting. The New South Wales Coalition government is ahead of the game with the foresight to work in the best interests of the people of NSW, by formally becoming NDIS partners with the Commonwealth in December, 2012. Making Every Australian Count is a monumental challenge, not just because of the additional cost, but because Australia has so much work to do with regard to both the built environment and attitudinal change across the whole of society, and at every level.

Unresolved Systemic Barriers

The idea of state borders as barriers faced by people and their families under an NDIS should be a thing of the past. However, because the funding of the NDIS does not adhere to the Productivity Commission's recommendation of one level of government to be responsible for the funding and delivery of NDIS, the barriers to freedom of movement remain because of the shared-funding model. Consequently, state boundaries will remain a hurdle for the portability of individualised disability funding packages, a hurdle to freedom of movement for employment and other options for people with disabilities and their families.

The question then arises: What happens if the other states cannot meet the financial demand of the Commonwealth to ante-up with their 'share' of the funding split and cannot sign up? We believe that NSW has dealt with this issue well, but for other states, not being able to sign up to the NDIS is a real fiscal possibility posing constitutional issues on the rights of people with disabilities to freely travel across state borders, for re-location, business and trade. These are very real issues for people with disabilities, issues that go Section 116 of the Australian Constitution.

The PC was aware of these constitutional issues when it recommended that the Commonwealth become the sole funder of the NDIS. These difficulties must be addressed within the legislation and in contracts with the states and territories for real freedoms and real life choices for NDIS participants.

The trial or launch sites

With some states being supported by the Commonwealth to hold the far cheaper cohort trials, Carers Alliance is concerned that these sites will be unable to provide critical data that will inform the full-scale national rollout of the Scheme. This clearly disadvantages those states and thereby diminishes their input into the way the NDIS is shaped. As a consequence of this, NSW and Victoria will actually be the on-the-ground designers and developers of the all-of-life service continuum in partnership with the Commonwealth.

The legislation in its current form

For those who will be eligible for support packages, the NDIS has the potential to offer greater certainty for the supports they receive. The NDIS signals a new beginning: the inclusion of and participation by people with disabilities in the social and economic life of Australia. It is therefore critical that the design of the NDIS and the supporting NDIS Agency be underpinned not only by the principles of voice, choice and control, but also the hitherto forgotten but vital choice; freedom of movement mentioned above.

The benefits of the NDIS must flow tangentially to the person requiring support, but also to the family/ carer. What the NDIS should do is not only provide the means for people with disabilities to live life their own way, but it must simultaneously break down systemic barriers thereby allowing families/carers to participate in remunerative employment, to pay tax, to asset build, to further their education and to participate in leisure and social activities.

The NDIS, properly implemented, would fundamentally transform the lives of people with disabilities and family-carers, many of whom are currently caught in a cycle of systemically-coerced impoverishment due to the inability to change the way things are.

The NDIS must provide opportunity to both people with disabilities and carer-families to make choices about how they will live their lives, just as other Australians do.

The truth is simply this: A good life for people with disabilities means a good life for their family, and for their primary care-giver and vice versa. For many people with significant disabilities there is an inextricable link between them and their families.

In the Universal Declaration of Human Rights the family is proclaimed the fundamental unit of society that must be nurtured and protected. However, notwithstanding this universal truth, and notwithstanding Australia's signing the UN Convention on Civil and Political Rights, the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, Australia has neglected and ignored the specific exhortations and obligations of those fine Conventions to assist people with disabilities and their families. That oversight, ignorance and neglect continues, as is borne out in this draft legislation

Australia's leaders and those who frame public policy have allowed families caring for a child growing into an adult with significant disability, to languish. They too are the Forgotten Australians, not just the person requiring support. The capacity of those families to participate in the life of Australia has been drastically undermined by the refusal of those in government to meet the obligations set out in the Conventions to which Australia is a signatory.

Carers Alliance believes the draft legislation for the NDIS has failed to determine that family/carers have a right to have their care role integrated into the participant's plan, particularly families of those with decision-making incapacity or people who, for whatever reason, cannot live alone. We find this remarkable given that the draft legislation enshrines unpaid care by stating *"what is reasonable to expect families, carers, informal networks and the community to provide*" without defining 'reasonable'. Does this then mean that this legislation must rely on the Courts to determine what is "reasonable"?

Without defining what is 'reasonable,' this legislation simply continues the *status quo*; whereby family/carers continue to be regarded as a passive group. A group which must surrender their lives to a lifelong-care role. This legislation gives no certainty that a reasonable level of external support will be provided to the person to whom they provide support so that carer-families can participate in the workforce, accumulate superannuation, buy a home and pursue activities that add value to their lives and to provide for their old age.

The legislation does not define 'carer', does not define 'reasonable' and certainly does not define family/carers as anything but passive providers of unpaid care for an indeterminate period. The legislation does not empower carer families to have the same rights and/or opportunities as other Australian families who do not have a family member/s with significant disability.

Clearly the legislation has not followed the recommendations of the Productivity Commission with respect to unpaid family carers. Other than for the family/carers of children, the legislation does not provide for the need to consult carer families for adults with significant disabilities who have decision-making incapacity and for whom the family has provided care, support, advocacy and social inclusion for their entire lives.

Informed choice with regard to people requiring supported decision makers

The legislation must provide to family/carers the right to exercise informed choice about decisions that will affect their lives; including the plan management with regard to the lives of people to whom they provide care and support, particularly if that support is to be ongoing as it would appear to be in this legislation.

It is families who have been the backbone of the informal support system and have forestalled the complete collapse of the formal disability system. In fact, more often than not, families have been, and remain the more significant providers to the support system. Under this proposed legislation, strangers are viewed as the preferred decision-makers in lieu of the family/carer. That the proposed legislation excludes the carer-family of a person with significant disabilities with decision-making incapacity unable make their own decisions without considerable support, shows that nothing has been learned by those who are supposedly trying to transform the disability support system.

This proposed legislation sidelines and excludes carer-families to a passive, observer role. It is laughable that the legislation deigns to recognise, acknowledge and respect carer-families and then relegates them to observer status, ignores their expertise and input and excludes them totally from the decision-making process when their family member is severely/profoundly disabled and incapable of decision-making in any meaningful value-adding way. Carer-families do not want to limit the lives of their family members with disability, they do not want to control them for controls sake, but they do want to limit those who would control and limit their lives for bureaucratic and service provider convenience. That carer-families are excluded is an indictment of the process that produced this legislation.

The first voice after the person with disabilities themselves must be carer-families, unless it is otherwise determined by judicial review that the family/carer is not acting in the best interest of their family member or where there is suspected abuse and neglect or where serious conflict arises. This legislation takes us back to the bad old days when it is/was assumed family/carers are less likely to act in the best interest of individuals, than total strangers, when in fact they have been acting in the best interest of the person with disabilities for the major part of their lives.

This legislation is a "back-to-the future" piece of law-making where people with significant disabilities will once again become captives of the care system. This particular section of the draft Bill smacks of the same "we-know-best" brigade of the past which saw the worst outrages of neglect and abuse perpetrated against vulnerable, helpless and voiceless people with disabilities out of sight of public scrutiny, where decisions were made "in club" and where in we saw the institutionalisation, degradation and alienation of people with disabilities from family and society. Is that shameful history to be repeated? Carers Alliance strenuously objects to the usurping of the role of the family at first instance without a defined measure that says they are not acting in the best interests and on the second, without judicial review. Family/carers are not just 'informal supports' for many people, they are partners in care and should be defined as such within this legislation.

Section 35 of the draft refers to a protocol for determining what support is considered reasonable and necessary after a determination of what is reasonable to expect of families, carers and others. How can determination of this be made without a carer assessment and without input by the family/carer on willingness or capacity to continue a prescribed level of informal support?

Many people with disabilities face such enormous challenges in their everyday lives and we view the NDIS, if flexible, as a means of turning these challenges into positive enablers.

Guardians as nominees

Public Guardians are an important part of a very complex service system. They do a difficult job; they are under-resourced for their often large, difficult and/or complex caseload.

An overworked Public Guardian can easily become a rubber stamp for service providers. An overburdened Public Guardian can make it impossible for them to adequately plan for each individual. With the sheer volume of caseload the Public Guardian all too often depends on the service provider to make available an accurate summary of a person's needs, wants, hopes, goals and dreams.

As we know there are good service providers and bad, there are service providers who openly support people as individuals and others who view people simply as a dollar value and manipulate the system for an outcome for the service provider.

Mindful of recent past history, Carers Alliance hopes Public Guardians will be mandated to work hand-in-hand with personal advocates who should be provided with appropriate opportunity to meet with, and to get to know the person under guardianship and to present their strengths and challenges to the Guardian in order to inform the Guardian's knowledge, distinct from to that of the view of service/care provider.

Carers Alliance believes that without this additional input from advocates, a person under guardianship needs two nominees in order to ensure that their voice is heard and/or their needs-properly reviewed in a timely manner.

The premise underpinning disability reform is to transform the disability service system into one of choice, giving ALL people with significant disabilities a choice in service provision. It is not acceptable for government or any of its agencies to force some people with significant disabilities to consume services dictated by government, while giving others freedom of choice.

Recommendation: The NDIS Agency must ensure that a person under guardianship has the benefit of an advocate in order to avoid decisions being made without any independent review, which was a feature of times gone by and to which we must be vigilant not to return.

A free market

Carers Alliance maintains that service provision must be developed along free market lines thereby ensuring the market develop into one that is dynamic, offering diversity and choice. If people or their agents make minor mistakes as part of the process this is simply a learning experience, to be viewed as such given that government and its Agencies will be part of the same learning experience. The sky will not fall in.

Carers Alliance recognises and commends the brilliant disability service providers who do a marvelous job in often difficult circumstances. However, it must be conceded, by virtue of the disability reform now underway, that there are service providers currently operating that should have been exited from the system quite some time ago. However, it is not within the scope of this submission to explore this truth.

Suffice to say Carers Alliance hopes that service providers whose services and programs are sub-optimal will cease to operate under an NDIS. This is inevitable if the NDIS is to be consumer-driven. A clientele empowered by transformative disability reform and offered choice will seek out and retain high-quality, forward-looking service providers, and those providing services that are innovative, person-centred, responsive and individual to their needs. Service providers unwilling to change will simply not survive in the NDIS world.

Registered provider supports

Carers Alliance feels that mandating only registered provider supports and services for any particular groups of service users is against the spirit of the recommendations of the Productivity Commission. Such restrictions on choice will deny access to many mainstream services, which are not disability-specific. Such restrictions will again lock people with disabilities into a sector without the fluidity that comes with choice and control.

Carers Alliance is concerned there is a move to restrict the choice of services and support for people with high level support needs (the 10% of people with significant disabilities currently living in community care residential settings and/or accessing community-based day-programs) thereby locking those clients into the inflexible block-funded model. This will encourage a discriminatory, two-tiered system wherein those with the least power will continue to be ‘captives of care’.

Recommendation: Rights based Legislation for all

It is imperative that the legislation is rights-based for all participants and that all people are provided with flexible options and not locked into traditional services unless for mandated community safety reasons.

Furthermore, if such a two-tiered system is permitted it will not compel changes in the mindset of those service providers who have regarded people with high-level support needs as being their exclusive 'market'. It will continue the stagnation of programs and stifle innovation for better service delivery, which has been a much overlooked object of the Commonwealth's *Disability Services Act* 1986.

Carers Alliance believes such a two-tiered system will make people with significant disabilities who need a high level of support more vulnerable to exploitation and discrimination and where services and support programs will stagnate and remain or become inflexible and not responsive to the changing needs of the person with disabilities.

Under cover of the 'complex management risk' excuse, the industry peak has produced a draft discussion paper where an NDIS for people with significant disabilities who need a high level of support will be allowed little choice, particularly if it can be mandated that only a registered 'disability' provider be used for their planning and service delivery.

A free market represents the future for people with disabilities. They have seen it, their families have seen it and they want that future. If service delivery is to remain dependent on registered service providers, the registration should not be too onerous so that people with disability can apply to be individual providers.

Few people with disabilities or their families would support some of the evocations contained in the NDS draft discussion paper entitled Choice and Risk in the NDIS. *This draft discussion paper appears to be a last-gasp of the self-interest and out-moded thinking which has be-devilled the disability sector and reflects badly on the peak body if this is its current thinking on the imminent introduction of a transformative disability reform. Carers Alliance expects better from this august body that represents some 700 disability service providers.*

Under the heading 'High-risk areas warrant close oversight' this draft discussion paper states: *"The highest risk areas affect far fewer people, probably one in ten NDIS participants* [1 Estimate based on people using accommodation support under the National Disability Agreement]. *These are people who rely a great deal on the quality of support provided in order to have any control or choice in their lives. The funding model alone is not a good predictor of outcomes for people who require high levels of personal support* [2 Personal disability support includes direct support with: wellbeing; daily household activities; meals; active inclusion in social, recreational and community experiences; and positive behaviour support. Rather than support that people without disabilities may also purchase such as cleaning, home maintenance and gardening support.], *including assistance with communication and decision-making or supervision.*

For these groups, it is what support workers say to them and do with them while providing personal support that makes the biggest difference to participation outcomes. Moreover, research at La Trobe University [3 Bigby, C. Clement, T. Making life good in the community: The importance of practice leadership and the role of the house supervisor. La Trobe University, Published by the Victorian Department of Human Services, 2007] *indicates that it is the quality and supervision of the workforce that will determine how much choice and control this group has in their lives.*

This analysis supports a strategy of creating a threshold of personal support needs, and specialist support activities such as communication support or decision-making support, above which a registered provider must be used (rather than direct employment or a non-registered provider)".

It must be noted that the one in ten service users discussed above are those who, because of the high costs of the services necessary to support them, will return optimum dollars to the service providers. It would appear that some service providers see choice as an anathema, and will set alarm bells ringing for all fair-minded Australians.

Carers Alliance believes the 'highest risk area' views in the NDS *Choice and Risk in the NDIS* discussion paper are antiquated, that such a system of service delivery is not ~~an~~ open and accountable one, which a properly implemented NDIS would make possible. The kind of thinking applied by the NDS paper means that for the highest-level care cohort the NDIS and person-centred planning and support may as well not exist, for them choice, voice and control will be just words, hollow and glib.

The NDIS is not about service providers, it is about service users, something seemingly lost for those people with high support needs in this draft discussion paper. For a shamefully long time people with significant disabilities have been powerless. They have been at the mercy of the vagaries of government and service providers with respect to what services they can access, when they can access them and where they can access them with little input as to what kind of services they want and need.

For people with significant disabilities the power of choice and control is the heart of a fair system of service and support.

This is how we believe the Productivity Commission envisioned a fair system and it is what will transform the lives of people with disabilities and carer-families. Service providers have nothing to fear and every reason to embrace the opportunities an NDIS will create for them to provide a choice-driven dynamic service delivery system that can be accessed freely and openly by people with disabilities.

Recommendation: The NDIS is not about service provider expectations. *No participant should be tied to registered service providers unless registration becomes less bureaucratic and less 'closed shop'.*

Complaints process

The NDIS Agency must ensure there is a complaints mechanism operating independently of itself and of the sector, to ensure that neglect, abuse and exploitation of clients, particularly those living in community care, does not occur. An independent external monitoring regimen must be established rather than the current cumbersome and inadequate state-based system that calls for little accountability from some sub-standard service providers. There must be mandatory reporting by the usual mandated reporters such as doctors, allied health agencies, health-care workers as well as disability service providers and disability support workers.

Without mandatory reporting the person with significant disability remains vulnerable and at risk. Any monitoring regimen must have coercive powers to access information and the power to sanction and to deregister an organisation/registered service provider. Mandatory reporting is often simply ignored for the captives of care in the disability sector and when reported, inadequate interventions occur as there are really no real penalties within the system and no body that has coercive powers that will ensure the flow of accurate and accountable information takes place.

Recommendation: A rigorous complaint system with coercive powers to deliver accurate information, making service providers accountable for their actions and the actions of their staff.

Advocacy

Not all people will need advocacy but for those who do it is imperative. The funding of advocacy is an integral part of ensuring the NDIS works for each individual, be it the participant or their family. While there is funded individual as well as systemic advocacy for people with disability, currently there is only systemic advocacy through Carers Australia and its affiliates for carer-families.

There is no formal or funded individual carer/family support and advocacy. The assumption by government that all families/carers can self-advocate has left many carer-families at enormous disadvantage and to the detriment of their family member as well. To presume capacity for advocacy by carer-families is to presume that most people across all disability types have the ability and skills necessary to self-advocate. If this were the case, there would be little need for advocates at all.

The importance of advocacy for all cohorts cannot be stressed enough.

Recommendation: There must be provision for advocacy for both families/carers distinct from that of their family members with disabilities in order to effectively engage with the NDIS Agency and other decision-makers to achieve the best outcome for their family member with significant disabilities.

Recommendation: Every client provided with NDIS packages must have access to a distinct funding stream for advocacy separate to their support package in order to reduce the barriers to engaging with the system.

The Agency

Bearing in mind that the NDIS Agency is the funder of services there must be an independent review tribunal to which individuals with disabilities/and carer-families can go for dispute resolution. It would constitute an egregious conflict of interest for the funder to have overarching power to dictate planning and simultaneously be the arbiter of the decisions it makes which might give rise to conflict, complaint or dispute.

Recommendation: It is imperative there be a separation of powers with regard to funding, planning, service provision and plan-management in order to avoid matters giving rise to conflict.

The CEO

The reality is that the powers vested in the CEO will be delegated and decisions made far down the bureaucratic chain rarely coming to his/her attention. For all intents and purposes it will be bureaucrats who will be making decisions. Accordingly, additional safeguards must be in place to ensure that prohibitive decisions can be escalated up the chain so that the CEO can give fair hearing.

Recommendation: Individuals must be provided with the means for review to go to the CEO.

Wording within the legislation

It is alarming that the word "should" is employed throughout the legislation in lieu of words that compel, like 'shall' 'will' and 'must'. This would indicate there is much elasticity and leeway as to what shall, must and will actually be done for people with disabilities. This needs urgent review.

Conclusion

Guardianship issues for complex needs

The legislation in no way addresses the matter of guardianship for people with disabilities who have decision-making incapacity. In this regard let's be clear on this, in the main, we are talking here about people with moderate to severe intellectual disability.

We have the situation in Australia where chronology overrides intellectual/developmental capacity. In other words on the day before their 18th birthday a youth with severe/profound intellectual disability who will have, for their entire life, been supported, nurtured, guided and cared for by their parents/carer-family and decisions for the best quality of life for them will have been made by their parents/carer-family. However, all that changes the following day when they turn 18. Suddenly, under the of laws of Australia they are left bereft of that decision-making capacity provided by their parents/carer-family because the day they turn 18 is that day that all parental authority, parental guardianship and parental financial management legally ends for them while all the circumstances of vulnerability, incapacity and disability persists.

At this point it becomes more difficult to enter into a contract on behalf of the individual for the most basic things – identity cards, medicare, banking, contracts, health services etc. at reaching majority age, the repercussions with respect to the legal standing of carer-families become disjointed and difficult.

Provision must be made in the NDIS legislation for seamless, plenary guardianship to be given to parents/carer-families when their young adults, who through their decision making incapacity would be targeted for Public Guardianship if problems arose.

This uncertainty must be eliminated because it causes undue distress and hardship. Without such plenary guardianship, the doors are often closed to carer-families. Of course provisions exist for Guardianship Tribunals to make decisions on guardianship as required however that is in the event of a dispute, or some situation that triggers the intervention of the state Guardianship Tribunals. If there were a legislative mechanism/means that bestows plenary guardianship to parents/carer-families of people with clear decision making difficulty at the attainment of the age of majority, the rights of people with disabilities would be better protected.

People with Disabilities must not be 'Captives of Care'

It was that great disability advocate and inspirational person with disabilities John Roarty who coined the term 'Captives of Care"

Carers Alliance in no way supports any regimen whereby people with disabilities remain/become 'Captives of Care'. This was the situation in the early part of the twentieth century and persists to this day in the mindset and for the convenience of policy-makers bureaucrats, service providers and government.

Carers Alliance sees this as the underlying theme to the proposed NDIS legislation and the paper prepared by NDS the peak body of disability service providers. This is extremely disturbing. It is a theme that negates the role of carer-families and considers that some people with disabilities are worthy of freedom of choice while others are not and must remain 'captives of care'.

The struggle for people with disabilities for control, voice and choice was powerfully portrayed in John Roarty's book *Captives of Care* published in 1981.

"... suffering and apprehension and fear was in reaction to the dominating, paternalistic, over-protective attitude of the authorities (the disability service provider)... That is what our story is about: domination and the power of authority, and our struggles to curb that power and assert our independence and our rights as human beings'...

Incrementally, things have changed for people with disabilities but John Roarty was right when he said: *'We still have a great deal of work in front of us and will have into the foreseeable future'*

That an NDIS is in prospect is testament to the work of so many people with a 'common cause'. However, in progressing people with disabilities to have control, choice and voice we must not forget those who cannot control, have no choice and literally have no voice. We must fashion change for all people with disabilities including those who, by the very nature of their disability, do not have control, choice and voice.

Carers Alliance agrees with John Roarty, that people with disabilities must not be and never again be *".... locked away – silent and out of sight.'...*

CHOICE: Is the transformative means to a better life for people with significant disabilities and carer-families. We at Carers Alliance trust no self-interested group will be given the power to deny this novel and powerful notion to those who have waited a lifetime. Choice is the future for people with disabilities and for those who care for and about them.

Maree Buckwalter

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