

# Office of the Public Advocate (Queensland) Systems Advocacy

## Submission to Department of Families, Housing, Community Services and Indigenous Affairs

For the National Disability Insurance  
Scheme Rules Consultation Paper

**March 2013**

# Interest of the Public Advocate for Queensland

The Public Advocate was established by the *Guardianship and Administration Act 2000* to undertake systems advocacy on behalf of adults with impaired decision-making capacity in Queensland. The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity (the adults) in all aspects of community life.

More specifically, the functions of the Public Advocate are:

- Promoting and protecting the rights of the adults with impaired capacity;
- Promoting the protection of the adults from neglect, exploitation or abuse;
- Encouraging the development of programs to help the adults reach their greatest practicable degree of autonomy;
- Promoting the provision of services and facilities for the adults; and
- Monitoring and reviewing the delivery of services and facilities to the adults.<sup>1</sup>

In 2013, there are approximately 114,000 Queensland adults with impaired decision-making capacity.<sup>2 3</sup> This vulnerable cohort includes adults with a disability, some of whom receive a government-funded or government-provided specialist disability service. The most common types of disability experienced by these adults are psychiatric disability (54%) and intellectual disability (26%).<sup>4 5</sup>

The majority (66%) of Queensland adults with impaired decision-making capacity have a profound or severe level of limitation with the core activities of communication, self-care and mobility.<sup>6 7</sup> This means that in addition to having impaired decision-making capacity, people require assistance to undertake, or are not able to undertake, some core activities in normal daily life.

## Position of the Public Advocate (Queensland)

As stated in my submission on the *National Disability Insurance Scheme Bill 2012*, the NDIS represents a significant step towards addressing the deficiencies of the current disability service systems that exist across Australia and advancing cultural change and genuine social inclusion.

Having said that, I am concerned that the introduction of the NDIS does little to address the fragmented nature of the broader service system within which it is being introduced despite its reliance on the agencies within this system to supplement the supports that the NDIS will provide to people with disability.

The current human services system lacks cohesion and is inequitable. People are channelled into different service systems in accordance with the defined target groups or service parameters of those systems, with many of them lacking the sophistication to determine and provide an appropriate mix of services to adequately respond to the holistic needs of the person. The services that are available differ from system to system and are often premised on historical service types that do not map to contemporary understandings. In many cases, they are also provided according to rigid models of service delivery that do not give sufficient consideration for the outcomes being sought by the person nor how to create an effective network of support and services to assist the person to achieve their goals.

The shortfalls of these systems often lead to services being provided in an *ad hoc* manner that does not address the causal factors underpinning the person's circumstances. Instead the current approach centres more on the 'type' of impairment experienced by the person rather than on understanding the 'nature' of their impairment and the broader circumstances that impact on their need for support.

<sup>1</sup> Section 209, *Guardianship and Administration Act 2000* (Qld).

<sup>2</sup> Australian Bureau of Statistics 2012, *Microdata: Disability, Ageing and Carers, Australia 2009*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>3</sup> Australian Bureau of Statistics 2008, *Population Projections, Australia, 2006 to 2101*, cat no. 3222.0, Australian Bureau of Statistics, Canberra.

<sup>4</sup> Australian Bureau of Statistics 2012, *Microdata: Disability, Ageing and Carers, Australia 2009*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>5</sup> Australian Bureau of Statistics 2008, *Population Projections, Australia, 2006 to 2101*, cat no. 3222.0, Australian Bureau of Statistics, Canberra.

<sup>6</sup> Australian Bureau of Statistics 2012, *Microdata: Disability, Ageing and Carers, Australia 2009*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>7</sup> Australian Bureau of Statistics 2008, *Population Projections, Australia, 2006 to 2101*, cat no. 3222.0, Australian Bureau of Statistics, Canberra.

As the Public Advocate for Queensland and in line with my responsibility for systems advocacy, the position I have detailed in this submission draws attention to some of the systems issues evident from the National Disability Insurance Scheme (NDIS) Rules Consultation Paper (the Consultation Paper).

As stated in the Consultation Paper, the NDIS is premised on the presumption that individuals have the capacity to make their own decisions. While this position is commended for its support of the *United Nations Convention on the Rights of Persons with Disabilities* and the principles inherent in Queensland's guardianship legislation, many of the processes associated with accessing support via the NDIS rely on an individual's capacity to understand and navigate the system accordingly, which is likely to present challenges for people with impaired decision-making capacity.<sup>8</sup> Furthermore, given that people with impaired decision-making capacity have the same rights as people with capacity, it is essential to ensure that all NDIS rules, policies and procedures accommodate and protect people who are unable to make their own decisions.

The *National Disability Insurance Scheme Bill 2012* (the Bill) and the Consultation Paper explain that people with disability will be supported to exercise choice and control in the planning and delivery of their support services and interactions with the NDIS Launch Transition Agency (the Agency). Without greater insight into Agency decision-making and further detail regarding how the NDIS will be implemented, it is difficult to determine whether people requiring assistance will actually receive an appropriate and adequate amount of support.

While the Bill and the Consultation Paper both recognise the need for the NDIS to operate within the context of other systems that exist to address needs not necessarily attributed to an individual's disability, it is not evident how the NDIS will promote greater responsiveness by these systems for people with disability despite its reliance on their responsiveness to determine what may be considered a 'reasonable and necessary' level of support for a NDIS participant.

A more inclusive and outcomes-focussed approach to the delivery of human services would generate increased opportunities for improvement and integration within and across systems, thus enabling more appropriate support to be provided to people with disability.

## Eligibility Requirements and Application Process

The NDIS will provide the support and care that people with a disability require in everyday life,<sup>9</sup> however not all applicants will satisfy the NDIS eligibility criteria. This may result in some people with a disability struggling to access and fund disability support services and could drive a need for state governments or other federally funded systems to fill the gap. It may also increase demand for mainstream and community services. Consideration should be given to the potential impact that ineligible NDIS applicants may have on the demand for other supports and services in the community.

The NDIS must include strategies for appropriately assisting and referring applicants who are ineligible for NDIS support and for building community capacity. A lack of accessible information and assistance to guide the navigation of government, non-government and private sector providers can compound the stress and frustration experienced by people with a disability, particularly those who also experience impaired decision-making capacity, as they attempt to identify and secure support services.

This may also be relevant for people who are eligible given the underlying premise that the Agency's assessment of what may constitute 'reasonable and necessary supports' for an individual carries with it the assumption that other systems of service delivery or support will be operating at an optimal level for each participant. In reality, this is rarely the case.

It is proposed that the NDIS will provide Australians with peace of mind that they will receive the assistance they require should they 'have or acquire'<sup>10</sup> a disability. Does the term 'have or acquire' suggest that the rules relating to the National Injury Insurance Scheme are the same as those for the NDIS, or does it simply refer to the situation where a person acquires a disability during their life e.g. a psychiatric disability? Rules regarding the proposed interaction between the two proposed schemes may be required to ensure clarity and manage the expectations of potential participants.

The proposed NDIS eligibility requirements are comparable to those applied in Queensland. Some NDIS applicants may therefore experience similar difficulties in satisfying the eligibility requirements. The difficulties experienced by some disability support applicants in Queensland have included, but are not limited to, the inability to provide satisfactory evidence of age and residence and difficulty in securing adequate evidence of their impairment/s.

<sup>8</sup> JFA Purple Orange 2012, *The Road to NDIS: Lessons from England about Assessment and Planning*, Julia Farr Association, Adelaide.

<sup>9</sup> National Disability Insurance Scheme 2013, *National Disability Insurance Scheme Rules Consultation Paper*, Commonwealth of Australia, Canberra, p24.

<sup>10</sup> National Disability Insurance Scheme 2013, *National Disability Insurance Scheme Rules Consultation Paper*, Commonwealth of Australia, Canberra, p1.

There is evidence in Queensland of individuals and families struggling to provide adequate proof of their age and residency. Some applicants do not have a copy of their birth certificate and cannot afford to purchase a copy. Examples of applicants who can have particular difficulty in providing documented evidence of their age and residency include people from Aboriginal and Torres Strait Islander backgrounds, people who experience chronic social and economic disadvantage, people who are homeless or who live in temporary accommodation, and people in contact with the criminal justice system.

The NDIS rules suggest that applicants may be permitted to supply evidence from existing assessments. The eligibility determination process can be complicated by the lack of detail in medical and other assessments about a person's impairment and the permanency of their impairment. Medical practitioners can be hesitant to provide a definitive diagnosis, which can impede the eligibility determination process. The lack of appropriate documentation about a person's diagnosis or impairment may present as an issue in the national scheme.

The application process, including the provision of required documentation, must be clearly communicated, streamlined and efficient, given the potential impact of a lengthy process on individuals, their families and carers. Appropriate assistance in navigating the process and submitting the required documentation must be provided to potential applicants, their families and carers where this is required. The difficulties in supplying appropriate documentation, including birth certificates, proof of residency or a detailed medical diagnosis can cause significant stress for some individuals and families. It can also lengthen the time taken to progress through the application process.

Neither the Bill nor Consultation Paper mention the potential need for a support person or substitute decision maker to submit an Access Request on behalf of a person with a disability (should the person be unable to complete and submit the request themselves). The inclusive, person-centred nature of the NDIS suggests that a support person or substitute decision maker would be permitted to make an application on a person's behalf, however this should be specifically addressed in the rules.

It is critical that the NDIS staff responsible for assessing the eligibility of potential participants have appropriate expertise, experience and training in conducting assessments. They must also be competent in responding to and supporting the differing needs of people with disability with respect to their ability to engage with and participate in the assessment process.

I strongly support the determination of disability on the basis of functional assessment rather than clinical diagnosis. The 'nature' of a person's impairment is of greater relevance to their need for support than their 'type' of impairment. More often than not, the impact of a person's disability is related to the inability of the person's surrounding environment, or a lack of necessary resources, to adequately respond to their needs. This can exacerbate the extent to which their impairment limits their participation in social and economic pursuits. The inherent challenge is how to reliably and consistently determine disability on the basis of a functional assessment.

The Bill specifies that to be eligible for support under the NDIS a person's impairment/s must affect their capacity for social and economic participation. This is a double-barrelled criterion as a person may have capacity in one area and not the other, for example, a person's impairment may affect their capacity for economic participation but not for social participation. In this situation, would the person's eligibility be compromised? Rules addressing this idiosyncratic criterion may be required to provide clarity for applicants and guidance for those assessing eligibility.

The NDIS rules must provide very clear parameters for the assessment of functional capacity, the capacity for social and economic participation and the permanency of impairment. Those responsible for determining a person's eligibility may experience difficulties in assessing these subjective criteria without fulsome and clearly articulated guidelines, particularly in relation to what constitutes a substantial reduction in functional capacity. I trust that submissions from specialists in this area and the work of the Select Council for Disability Reform will inform the development of appropriate, equitable and reliable rules.

The assessment tools used to determine the eligibility of a person with an Indigenous or other cultural background must be adequate and culturally appropriate. Westernised assessment tools can be culturally biased due to language and general communication differences, education levels, remoteness, lack of baseline measurement and the inability of tools to allow for personality, family, community and cultural differences. A person should not be denied access to the NDIS due to discriminatory assessment tools and processes.

The Bill specifies that a person must have a disability that is attributable to a defined list of impairments to satisfy eligibility requirements, however the Consultation Paper only discusses functional assessments. Irrespective of whether the Agency will determine the nature or permanency of an applicant's impairment, rules relating to diagnosis are likely to be of value, considering that the Bill suggests that a person's diagnosis will soon be a legislated eligibility requirement. It is important to recognise however that, as noted earlier, it can be difficult for applicants to obtain a definitive diagnosis or a diagnosis with adequate detail. Furthermore, I would recommend caution should the NDIS propose to generate a definitive list of 'eligible diagnoses'. The experience in Queensland has demonstrated the difficulty in defining an exhaustive list that can be relied upon by staff conducting assessments given that, as referenced earlier, the experience of disability is impacted more by the 'nature' of an individual's impairment than the 'type'.

## Supporting Decision Making and Nominee Arrangements

I welcome the inclusion of 'Supporting Decision Making' in the Consultation Paper. It is important that the NDIS allows for supported and/or substitute decision-making in certain circumstances and includes protections from potential abuse, neglect or exploitation. I am pleased that the NDIS will formally recognise the existence of court-appointed guardians (for personal and health care matters) and administrators (for financial matters).

In addition to placing the person with a disability at the centre of decision-making, every effort must be made to understand the surrounding circumstances and ascertain the true wishes of the person with impaired decision-making capacity prior to decisions being made on their behalf.

I support the NDIS Agency's recognition of the potential for fluctuating decision-making capacity and for not assuming the permanency of a person's need for supported or substitute decision-making. A person's decision-making impairment may be a temporary situation or could fluctuate over time. Accordingly, I commend the Agency's commitment to 'build people's skills, experience and confidence to make choices and take greater control'.<sup>11</sup>

I respectfully suggest that the use of the term 'people without legal capacity'<sup>12</sup> in the NDIS rules be amended to 'people with impaired decision-making capacity'. The reasons for this include:

- The term 'impaired decision-making capacity' is widely accepted and utilised by courts, guardians, administrators, families/carers, advocacy groups, government and service providers;
- The suggested term provides a more accurate description of the cohort;
- The suggested term is more respectful of the people to which it refers;
- The suggested term is a more positive manner by which to reference the cohort; and
- The suggested term is likely to be more easily understood by people who are unfamiliar with the cohort.

The Paper outlines the following four options to accommodate the needs of a NDIS participant who is unable to make their own decisions:

1. A nominee, or substitute decision-maker, arrangement initiated by a NDIS participant and accepted by the NDIS Agency, or a nominee arrangement initiated by the NDIS Agency, taking into account the person's wishes;
2. Recognition of formal legal arrangements that are in place for people with impaired decision-making capacity such as the Public Trustee and guardianship arrangements;
3. In strictly limited circumstances, the NDIS Agency making a decision to assign an appropriate person to act as the representative of the NDIS participant when they are unable to be supported in their decision-making and unable to consent to a nominee (without the need to apply for formal guardianship); and
4. Consistent with other areas of law and administration, parents will be legally responsible for children under 18 years of age.<sup>13</sup>

<sup>11</sup> National Disability Insurance Scheme 2013, *National Disability Insurance Scheme Rules Consultation Paper*, Commonwealth of Australia, Canberra, p25.

<sup>12</sup> National Disability Insurance Scheme 2013, *National Disability Insurance Scheme Rules Consultation Paper*, Commonwealth of Australia, Canberra, p24.

<sup>13</sup> National Disability Insurance Scheme 2013, *National Disability Insurance Scheme Rules Consultation Paper*, Commonwealth of Australia, Canberra.

I have two primary concerns regarding the first option. The NDIS Agency should not have authority to 'accept' the choice of nominee of a NDIS participant. The ability to do so will be counterintuitive to the right of a person to choice and control. The role of 'accepting' a nominee should be an administrative process, not involving any subjective decisions. Notwithstanding this, there may be a role for the Agency to decide whether to accept an identified nominee in situations of crisis or where evidence of abuse, neglect or exploitation exists. In these acute circumstances, the Agency must have strict protocols governing their actions, including the extent of decision-making. These protocols should recognise and utilise existing state guardianship systems where appropriate and relevant, for example, in cases involving adults with impaired decision-making capacity.

In recognition of this, the role of the NDIS Agency in initiating a substitute decision-making arrangement should also be administrative only, for example, in the situation where an informal or court-appointed decision-maker approaches the Agency to become a NDIS nominee. The Agency should never be given the power to determine if a person requires a substitute decision-maker. This would be in conflict with guardianship legislation in numerous jurisdictions. A legal determination of a person's capacity to make decisions should only be made by the relevant agencies in accordance with state guardianship legislation.

Furthermore, in recognising and adhering to state guardianship legislation, it should be noted that the first option is subject to the second option. In the situation where a person has a guardian for personal and health care matters, a nominee arrangement should not be entered into with any third party other than the court-appointed guardian. A court-appointed substitute decision-maker must be considered prior to other options when examining ways to accommodate the needs of people with impaired decision-making capacity.

The wording of the second option should be amended to read 'adherence to legal guardianship and administration arrangements for people with impaired decision-making capacity such as private guardians and administrators, the Adult Guardian and the Public Trustee'. The NDIS Rules should not just recognise guardianship and administration arrangements, but abide by them. This includes the underlying principles of state guardianship and administration legislation. The suggested amendment provides a fuller and more accurate description of guardianship and administration arrangements.

I strongly oppose the third option, which affords the NDIS Agency the power of the Queensland Civil and Administration Tribunal, and of its equivalent in other States. Under Queensland's *Guardianship and Administration Act 2000*, the Queensland Civil and Administration Tribunal determines whether a person has impaired decision-making capacity relating to specific decisions, based on medical and other evidence. The Tribunal also appoints a person to act as a guardian for a person with impaired decision-making capacity to ensure the interests of the adult with impaired decision-making capacity are protected and their needs are met.<sup>14</sup>

It is not appropriate in any circumstance for the NDIS Agency to decide on the need for a substitute decision-maker or who is the most appropriate person to fulfil the substitute decision-maker role. Such a power would directly contravene state guardianship legislation.

Similarly, I do not support the proposed ability of the Agency to determine when a child is capable of making their own decisions, nor do I support the ability of the Agency to appoint a person other than a parent, or existing carer or court-appointed guardian to make decisions relating to the care and support for a child. Such abilities may infringe on the role of the Family Court of Australia and encroach on Queensland legislation, and potentially also that of other state jurisdictions.

The criteria to guide the appointment of a nominee should direct the Agency to respect the choice of nominee of a NDIS participant, adhere to state guardianship and administration legislation and pursue supported decision-making prior to initiating substituted decision-making arrangements wherever possible.

As with guardians and administrators, the nominee of a NDIS participant may have one of many different relationships with the person. They may be an immediate or extended family member, a friend, a carer, an advocate or someone else who has a genuine and continuing interest in the welfare of the person. The rules should recognise and accommodate the diverse relationships that nominees may have with the NDIS participant.

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<sup>14</sup> Queensland Civil and Administration Tribunal 2011, *Guardianship for Adults*, Department of Justice and Attorney-General, viewed 15 February 2013, <<http://www.qcat.qld.gov.au/matter-types/guardianship-for-adults-matters>>.

The rules should include provisions to enable the Agency to be responsive to identified situations of crisis, abuse, neglect and exploitation. Procedural flexibility, or alternative procedures, may be required in crisis situations and the appointment of a nominee should be suspended if they are suspected of abusing, neglecting or exploiting the NDIS participant. The suspension should only be in place while the matter is investigated and should be lifted if there is no evidence of abuse, neglect or exploitation.

Some NDIS participants may have an enduring power of attorney, a statutory health attorney, a court appointed guardian for personal and/or health care matters or a court appointed administrator for financial matters. In these situations, the Agency must appoint the identified attorney or guardian as the participant's nominee. The Agency must not appoint anyone else into the role of nominee as the appointment will be in conflict with existing legislative instruments.

The Consultation Paper inquires as to whether a nominee appointment should be for a fixed period or if the appointment should be regularly reviewed. The rules should accommodate both options and be responsive to the situations of NDIS participants.

There should be similar flexibility in time-frames relating to the appointment of a nominee, with these decisions being guided by the wishes of the individual, responsive to the potential for fluctuating decision-making capacity by the individual and/or reflective of appointment time-frames for individuals with state appointed guardians and/or administrators. All appointments should be periodically reviewed to ensure the ongoing appropriateness of the appointment in light of changing personal circumstances, increased autonomy of the participant or the expiration of relevant legislative instruments.

## Participant Plans

I commend the Agency for recognising that some participants will have a clear view of their goals and aspirations, while others may require assistance to recognise their possibilities. As highlighted in *Disability Expectations: Investing in a better life, A Stronger Australia*, some people may require resources to assist them to envisage a good life for themselves. This is particularly relevant for individuals and families who have 'experienced years of passive service reciprocity and whose personal horizons of what is possible may have diminished'.<sup>15</sup>

In addition to the compulsory statements of goals, aspirations and supports, a Participant Plan should also document other details relating to the individual and evidence that the NDIS Plan Principles have been upheld. For example, it might be valuable to document the degree to which the Plan was directed by the participant (including the degree of input by others and the support provided to enable the participation of the NDIS participant), the degree to which the participant is able to execute the Plan (e.g. make service provider choices, coordinate supports from different providers, etc) and when the Plan will be reviewed (or under what circumstances it will be reviewed).

The Consultation Paper recognises the need for the Agency to make consistent decisions in determining the 'reasonable and necessary supports' for NDIS participants. It does not elaborate on:

- the level of care the Agency reasonably expects families, carers, informal networks and the community to provide;
- the criteria that will be used, or the weighting that will be applied to factors, when determining if a support is reasonable;
- how the Agency will balance value for money with the choice and control of individuals;
- how the Agency will weigh the cost of a support against the immediacy of achieved outcomes; or
- the determination of value for money for supports provided to people living in regional and remote areas.

'Reasonable support' is a subjective concept and will require clear assessment guidelines to ensure rigorous and equitable decision-making. In the interest of transparency, the Agency should provide greater detail on how it will practically assess whether a support is reasonable (for example, a clearly articulated statement of minimum standards), taking into account the issues highlighted in the previous paragraph.

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<sup>15</sup> PricewaterhouseCoopers 2011, *Disability Expectations: Investing in a Better Life, A Stronger Australia*, Pricewaterhouse Coopers, Australia, p34.

There is an urgent need for further information for applicants and their families, carers, etc to assist in managing expectations regarding the extent to which the NDIS will provide for the care and support that people may be seeking. It is clear from my discussions with individuals, families/carers and staff from service organisations in Queensland that many people do not understand what is meant by the term 'reasonable and necessary supports'; nor do they understand how this will be assessed.

The Bill indicates that a decision regarding whether supports are reasonable and necessary takes into account the appropriateness of other systems or agencies to support a person.<sup>16</sup> The determination of the most appropriate system or agency includes consideration of the legal requirements of other systems or agencies to support a person with a disability [Chapter 3, Part 2, Division 2, Clause 34 (f ii)].<sup>17</sup> This suggests that the NDIS Agency could request service 'adjustments' by another system or agency if there is evidence of discrimination based on the legal requirements of that system or agency to provide support to people with a disability.

However, the Bill does not provide power to the Agency to enforce changes to other service systems and agencies so it is assumed that the only avenue of enforcement is through normal legal processes. Clarity on the power of the Agency in such circumstances is required. Similarly, consideration may need to be given to current federal financial arrangements and the associated performance measurement indicators underpinning other federal systems such as health, education, etc. to facilitate a more integrated approach to service delivery for people with disability.

Failure to address the shortcomings of those systems that provide the necessary supplementary supports for people with disability will perpetuate the already fragmented nature of the broader human services sector and limit opportunities to facilitate improvement in the lives of people with disability.

A Participant Plan comes into effect when the Agency has received the two compulsory statements and approved the statement of participant supports. The Agency's role should be limited to ensuring appropriate financial accountability for the use of public monies and, in accordance with this, the Agency should only have authority to the extent of ensuring that services purchased using NDIS funds can be appropriately mapped to the assessed needs of a participant. The Agency should never be given authority to make subjective decisions about the lifestyle goals of a participant.

The development and implementation of a Participant Plan for someone with an Indigenous or other cultural background should accommodate their linguistic and cultural needs and allow them to exercise their choice and control of disability supports in a way that is appropriate to their circumstances and cultural needs. This includes family and community decision-making practices and alternative approaches to the delivery of disability support services.

In the situation where a statement of support is not fully approved, the Agency must clearly communicate which elements of the support statement are not approved and the reasons for its decision. The provision of such information is important to ensure the participant can make an informed choice about whether to accept the decision or seek a review of the decision.

It is important that the Agency's role in developing and actioning Participant Plans does not extend to making subjective decisions about which organisation/s or individual/s will provide a service to the participant. The Agency should, however, provide support for a participant (when required) to make decisions regarding choice of service provider.

The Consultation Paper does not outline any rules relating to the review of a Participant Plan, other than one relating to the circumstances that will trigger a review. The review of a Participant Plan should be conducted according to clear rules and guidelines to ensure the process is systematic, thorough and equitable. It should revisit the statements of goals and aspirations and supports, and a participant's living arrangements, informal supports and social and economic participation to ensure the continued appropriateness of the statement of participant supports. A review should also support the participant to consider the outcomes they have achieved, their relationships with family and their support network and their autonomy, independence and resilience.

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<sup>16</sup> National Disability Insurance Scheme 2013, *National Disability Insurance Scheme Rules Consultation Paper*, Commonwealth of Australia, Canberra, p15.

<sup>17</sup> *National Disability Insurance Scheme Bill 2012*.



The Bill specifies that if a participant provides the Agency with a revised statement of goals and aspirations, the Agency will respond by providing a revised Plan containing the updated statement of goals and aspirations and the statement of supports as per the existing Plan.<sup>18</sup> The provision of the updated Plan appears to be an administrative exercise as the Bill does not commit the Agency to re-examining the suitability of existing supports in light of the revised statement of goals and aspirations. The conduct of a re-examination should be considered in light of the Plan being a financial accountability tool of the Agency.

The Consultation Paper does not discuss any rules relating to the complaints process available to NDIS applicants or participants should they not be satisfied with a decision or action of the Agency in relation to their application for support, participant plan or approved supports. The Agency should have a system allowing for, and rules relating to, a complaints process to support open and transparent decision-making processes and ensure all complaints are treated respectfully and equitably.

## Situations of emergency or crisis

People within the community, including people with a disability and people with impaired decision-making capacity, can experience crisis and emergency situations. The circumstances surrounding such situations can include family disputes, violence, homelessness, child relinquishment, abuse or neglect, personal trauma, suicidal behaviour, mental health issues, urgent financial need or breakdown of support arrangements.

It is genuinely concerning that the Bill and Consultation Paper are both silent on the issue of emergency and crisis situations for people with a disability. There does not appear to be any provisions for responding to this need in the event that a person with a disability or their family presents to the Agency in a situation of emergency or crisis.

There may be a need for the Agency to provide appropriate and immediate assistance to a person in an emergency or crisis situation. The Agency should have protocols and rules in place to assist people in emergency or crisis situations to access short-term support services. In addition, Agency staff should have appropriate training to enable them to competently respond to the urgent needs of people in emergency and crisis situations.

The types of assistance afforded by the Agency could include information and referral services, access to emergency support services, etc. People in emergency or crisis situations typically require immediate support services for their protection and to prevent further deterioration of their circumstances. Their immediate needs must be addressed so their situation can stabilise and allow for planning for longer term and more permanent arrangements.

It should also be recognised that people in such circumstances may also need to be supported to access longer-term sustainable supports through the NDIS and/or other more appropriate systems of response. The Agency should recognise this and ensure appropriate processes are in place to do so, either concurrently or subsequently to assisting the person with the emergency or crisis situation.

## Full implementation of the Scheme

The Consultation Paper has a strong focus on the NDIS launch sites. It is therefore difficult to determine the real opportunities and challenges that may be encountered in fully enacting the NDIS, including its long term sustainability and the full impact on Australians with a disability. Information regarding the federal government's intention to retain or alter the launch site rules for the full enactment of the NDIS is required.

The Consultation Paper briefly discusses the NDIS continuity of support arrangements in launch sites however it does not elaborate on the continuity of support available through the fully enacted NDIS. Is it proposed that these continuity of support arrangements will be extended to the full roll-out of the scheme?

The financial sustainability of the NDIS could be significantly impacted by the provision of support to people who become an NDIS participant through continuity of support arrangements, particularly if it is proposed that these arrangements extend to the full roll-out of the NDIS. The number of people requiring continuity of support and the aggregated cost of their support will not be fully realised until the full roll-out of the scheme.

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<sup>18</sup> National Disability Insurance Scheme Bill 2012.

Will people in states that did not participate in the launch be extended the same access to continuity of support arrangements as those residing in launch sites? The failure to do so could constitute discrimination, particularly if people receiving continuity of support through a launch site became permanent NDIS participants and those from non-launch sites do not achieve that status.

The Bill and Consultation Paper both place significant emphasis on the financial sustainability of the NDIS. In addition to the above points regarding continuity of support arrangements, the financial viability of the scheme may also be impacted by absorbing the responsibility for people currently accessing high-cost state arrangements, should these costs not be fully realised or accurately predicted. Although the numbers of such individuals in Queensland are relatively low, the relative cost of their support far exceeds the 'upper limits' of nominal funding bands for support arrangements, particularly those associated with the provision of 24-hour accommodation support.

The ability of a NDIS participant aged 65 years or older to choose to be supported by the aged care system or remain supported by the NDIS may also have a significant impact on the system's financial sustainability. Presumably, under this arrangement a person receiving NDIS support would not experience any change in the supports they receive once they turn 65 years (should their support needs remain the same), however the funding of these services would shift from the NDIS to the aged care system (to maintain the financial viability of the NDIS). Should a person's needs change and become better supported through the aged care system, then the Agency should connect the person with the aged care system in line with the Agency's functions.

## Concluding Comments

Overall, I remain pleased to provide my support for the introduction of a National Disability Insurance Scheme and commend the Australian Government for its commitment to pursuing more effective means by which to support Australians with disability to achieve quality of life outcomes.

I would respectfully recommend however that further thought needs to be given to addressing those issues that have the potential to undermine the sustainability of the NDIS including, but not limited to, building capacity within the supplementary systems through which people with disability access support.

I support the Agency's recognition that some NDIS participants may require supported or substituted decision-making, however I have concerns regarding the proposed options to accommodate people who are unable to make their own decisions as they do not appear to give due consideration to established state guardianship legislation, nor promote adherence to same.

Further to this, I do not support the proposed ability of the Agency to select a nominee to act as a person's representative as this undermines existing guardianship and administration legislation. There are legislated processes and evidence requirements for the determination of a person's ability to make decisions and the most appropriate person to be their guardian or administrator. In accordance with this, the Agency must ensure adherence to existing substitute decision-making arrangements for a person with impaired decision-making capacity where these are established in accordance with state guardianship legislation.

I welcome the proposed determination of disability on the basis of functional assessment, however there must be clear rules for the assessment of functional capacity. There must also be clear and equitable rules to guide decisions around 'reasonable and necessary' supports.

Furthermore, the NDIS eligibility requirements and application process must not be a barrier to potential applicants accessing support. To this end, the Agency should ensure that the requirements and processes are easily understood, clearly documented and not overly burdensome for potential applicants, their families and carers. There is also a need to have clear review and complaint mechanisms in place.

Consideration must be given to addressing the short-term needs of people with a disability who experience an emergency or crisis situation. In addition, there should be an examination of the potential impact of people in emergency or crisis situations on the Agency and on other mainstream and community services. The omission of response mechanisms for such situations in the proposed national system could drive a need for state governments to fill the gap and also increase demand for mainstream and community services.

I trust that the NDIS Advisory Group and Expert Group on Quality, Safeguards and Standards will continue to consider the needs of people with impaired-decision making capacity as they work to protect this vulnerable cohort within the new national system.

Notwithstanding the intention of the NDIS, the human services sector remains fragmented and inequitable. Effective systems change will only occur when the framework for, and delivery of, human services takes an outcomes-focussed approach that considers the interplay between systems and addresses the fundamental need for integrated and cohesive service delivery whereby a person's needs are considered holistically instead of delineating a person's needs according to artificially-constructed system parameters designed more for bureaucratic and jurisdictional purposes.

I look forward to the opportunity to provide comment on further details of the NDIS as they become available, in the interests of ensuring that the implementation of the NDIS meets the needs and upholds the rights of those people it is being designed to serve.



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