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National Disability Insurance Agency (NDIA)
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Carers NSW welcomes the opportunity to provide a submission in response to the *Consultation Paper: Supporting you to make your own decisions* (the Paper). This submission focuses on the many and varied impacts of decision making support on family and friend carers, who are often relied upon for such support by both NDIS participants and the National Disability Insurance Agency (NDIA).

It explores the involvement of carers in participant decision making, as well as the supports required to ensure that the rights of people with disability, and their carers, are upheld simultaneously. This submission also emphasises that carer involvement in decision making does not need to equate to a reduction in the autonomy of people living with disability.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Carers NSW developed this submission with input from a range of stakeholders including members of the NSW Carers Advisory Council as well as Michael Perkins and Jane Lonie (Autonomy First Lawyers: Medico-Legal Capacity & Capability Clinic), Susan Cochrane (Relationships Australia National Office), Megan Frost (Relationships Australia NSW), and April Creed and Rebecca Glover (ExSitu).

Thank you for accepting our submission. For further information, please contact Madeleine Gearside, Policy Officer at madeleineg@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,



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Introduction

Carers NSW believes that the rights of individuals receiving care – including participants supported under the National Disability Insurance Scheme (NDIS) – are just as important as the rights of the family members and friends who support them (their carers). As such, we believe that the rights of both parties should be upheld. In many cases, the interests of carers and the people they care for intersect, however we also acknowledge that sometimes they are at odds.

As the peak non-government organisation for carers in NSW, carers' rights are the focus of Carers NSW; in particular, carers' rights in relation to self-determination and privacy, where carer and care recipient rights most commonly conflict. In Carers NSW experience, the contexts in which this occurs is in the determination of cognitive capacity and consent with respect to decision making and information sharing. This submission focuses on how the rights of carers and the people they care for can be balanced in the context of decision making.

The NSW Carers Charter¹ and the Commonwealth Statement for Australia's Carers² each state that the valuable contribution of carers should be recognised and supported. They also stipulate that the relationship between carers and the people they care for should be respected, and carers should be considered partners in care, with Government bodies and providers acknowledging carer knowledge and experience.

Throughout the duration of a caring relationship, the intersection of the rights of carers and people with disability is common. However, when there is conflict, there is a risk of having one party's rights placed above the other's, with potential implications for both parties' wellbeing and safety. In these circumstances, it is fundamental that any intersection or conflict is considered holistically, so that barriers to achieving rights for carers are removed and the best interests of the care recipient are upheld.

Background

Carers NSW recognises that not all people with disability receive informal support or would identify with having a 'carer'. However, family members and friends are important in the lives of all Australians, and the Australian Bureau of Statistics (ABS) has found that the majority of Australians with a reported disability who need assistance receive at least some of that assistance from a family member or friend; in many cases, on a daily basis.³ More than one third (37.4%) of primary carers also have a reported disability themselves, more than twice the rate of non-carers (15.3%).⁴

For many people with disability, the care provided by family members and friends plays a critical role in supporting their individual wellbeing, autonomy and self-determination. In addition to providing direct personal care and other practical and emotional support, carers are often active in supporting people with disability to navigate, access and coordinate NDIS, mainstream and specialised services, as well as supporting participation in the community, and in education and employment. Many carers are also involved in the broad spectrum of decision making, which will be explored in detail in this submission.

Data from Carers NSW 2020 National Carer Survey⁵ shows that of the carers providing support to a person with disability, over 80% provide support with cognitive and emotional tasks (including

¹ Carers (Recognition) Act 2010, Schedule 1 NSW Carers Charter

² Carer Recognition Act 2010, Schedule 1 The Statement for Australia's Carers

³ Australian Bureau of Statistics (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset, available online at: www.abs.gov.au

⁴ Ibid.

⁵ Carers NSW (2020). *2020 National Carer Survey: Summary report*. Available online at: <http://www.carersnsw.org.au/research/survey>

decision making) and nearly three quarters provide assistance with communication (including reading and writing tasks). Additionally, nearly 65% are involved in supporting the person they care for with finances, and the same percentage are involved in handling their finances directly. Over 70% are involved in advocating for the needs of the person they care for and providing support with behaviour. It is also important to note that around 10% provide support with language interpreting, another key consideration in relation to capacity and decision making.

Carers responding to the Survey who support an NDIS participant provide, on average, nearly 60 hours of informal care per week. Around 85% of carers of people with disability also regularly invest time in administration, and organising supports and services for the person they care for, and a similar percentage report spending time on coordinating support services and formal care workers.⁶

This data indicates the depth and intensity of involvement by carers in the lives of people living with disability, including those who are supported by the NDIS. It shows that many carers are already providing crucial support that contributes to the safety and wellbeing of the person they care for. Many of the supports listed above relate in some way to cognition and decision making. A lack of recognition of this support is detrimental to both carers and the people they care for.

This submission will highlight the urgent need for adequate support for carers, to ensure they can carry out decision making support, alongside the other care they provide, safely and sustainability, and in a way that upholds the rights of carers and participants.

Legal framework and definitions

Carers NSW views decision making as a fundamental human right, and fully supports autonomy for all people with disability. Autonomous decision making is underpinned by the concept of self-determination, an increasingly central principle in the ongoing redesign of formal care service systems. Self-determination seeks to overcome a default position that many carers and other often well-meaning parties have taken in 'speaking for' people with disability and other vulnerable groups, which has in many cases led to disempowerment and indignity, and in some cases, abuse and neglect.

The growing focus on self-determination and rights of people receiving care will significantly increase autonomy and opportunities for many people who have traditionally faced discrimination and systemic inequality. However, the ability to balance carer and care recipient rights within these systems is becoming increasingly challenging; there is often little scope to acknowledge or address the independent rights and needs of carers as individuals themselves.

Principles of mental capacity

In the context of decision making, current policy and practice generally involve the presumption of capacity without substantial documentation to the contrary. Governments and service providers are intentionally moving away from traditional substitute decision making models such as guardianship, in favour of supported decision making approaches, which prioritise enabling people living with cognitive impairment to express their needs and preferences. Carers are expected to play a supportive role in this process, however, little guidance tends to be provided to carers on exactly how to ensure a person's preferences are adequately captured and conveyed.

In essence, within a supported decision making paradigm, all practicable steps should be taken to support and build the capacity of a person living with cognitive and/or communication impairment so that their needs and preferences drive decision making, rather than the needs and preferences of

⁶ Carers NSW (2020). *2020 National Carer Survey: Summary report*. Available online at: <http://www.carersnsw.org.au/research/survey>

their informal and formal providers of support. Decisions considered undesirable or unwise by other parties should be viewed in light of the concept of 'dignified risk', with the 'best interest' decision making paradigm considered to be a last resort.

Carers NSW supports the increased agency of people with disability in making choices that affect them, provided that the carers who are expected to support this process are provided adequate information and support to facilitate this, and are treated with respect and dignity. Clarity and consistency with regard to the implementation of decision making support is also paramount, not only for the benefit of carers, but also to ensure effective support of people with disability.

Legally recognised support roles

Inconsistent provisions within State and Commonwealth legislation, alongside inconsistent policies and practices within service agencies across the two levels of government, create confusion and ambiguity for participants, carers and service providers. Further conflict is noted where there is a mandate that family, often carers, participate in supporting participants, but there exists a lack of clarity with regards to the rights of those same carers to participate in decision making and receive adequate information relevant to their provision of such support, and their caring role more broadly.

Across different states and territories in Australia, a number of formal appointments and roles are defined in legislation, providing carers and others specific rights and responsibilities with regard to decision making in order to safeguard the wellbeing of people who require this support. Such appointments may be made in relation to lifestyle, health, medical and/or financial decisions. It is preferable from a self-determination perspective that persons deemed to have legal capacity appoint a formal representative ahead of time so that this role is clearly defined before cognitive decline impacts on decision making. Legal appointment is increasingly considered a last resort, with a prioritisation of less formalised supported decision making measures wherever possible.

Varying appointments at state and territory level do not correspond well with policy and legislation at Commonwealth level, where the responsibility for policy and service delivery now sits for nearly all direct care services, causing much confusion and administrative complexity. The *National Disability Insurance Scheme Act 2013* (NDIS Act) recognises the requirement in some circumstances for a participant or National Disability Insurance Agency (NDIA) representative to appoint a 'nominee' "to act on behalf of, or make decisions on behalf of, a participant". This measure is framed as a last resort, only considered "when it is not possible for participants to be assisted to make decisions for themselves."⁷

While it is important to consider capacity on a spectrum, and not to remove or reduce a person's decision making power without due consideration, the limited and inconsistent interaction between Commonwealth designations and state and territory appointments can, for carers acting with or on behalf of the person they care for, add multiple additional layers to already complex navigation between service systems. This may also lead to unnecessary delays in decision making and support provision for the care recipient.

⁷ NDIA (2019), *Guardians and nominees explained*, available online at: <https://www.ndis.gov.au/understanding/families-and-carers/guardians-and-nominees-explained>, last updated 5 November 2019.

Privacy

The increasing emphasis on supported decision making and consumer direction has also resulted, in many cases, in a greater reluctance than in the past for government agencies and service providers to exchange information about care recipients with carers without the care recipient's explicit consent. Privacy and confidentiality is, of course, paramount in all service interactions, especially where sensitive information being shared may compromise an individual's self-determination, dignity or safety. However, Carers NSW is also concerned that in some cases, principles of privacy and confidentiality are over-emphasised to the detriment of information sharing with carers, especially where information may be critical in enabling them to fulfil their caring responsibilities.

"[Professionals] exclude me as a carer from decision making until there is a big problem, then they want my input."

– 2020 National Carer Survey respondent

Where challenges establishing legal or mental capacity exist alongside rigid, risk averse systems, this can result in information about participants' assessment and care planning being automatically withheld, even when such information may be critical in order for carers to provide timely, safe and effective care to support the participant. A lack of appropriate and ethical information sharing may have a detrimental impact on care recipient outcomes holistically. Continuing to care without key information can also have implications for carer wellbeing and safety, and may negatively impact on the sustainability of the caring role.

While participants should maintain their right to privacy, this must in some cases be balanced with the importance and appropriateness of information sharing for safeguarding purposes. Given the complexity in relation to information sharing, there is an identified need for improved training and practical support for agency staff to promote compliance under current legislation and ensure best outcomes for both participant and carer. Additionally, decisions pertaining to privacy and confidentiality require sound professional judgement; therefore a stronger focus on ethics training may be beneficial.⁸

Impacts for carers

Whilst the person most affected by a decision is the decision maker – in this case, the NDIS participant – it is important to recognise that carers can also be affected by decisions related to assessment and support planning. This is particularly the case where the outcome of a decision will impact on their caring role and responsibilities.

Qualitative data from the Carers NSW 2020 National Carer Survey⁹ highlights a range of experiences and impacts for carers who provide decision making support to a person with impaired capacity. Carers reported a lack of adequate information sharing and communication by professionals, which complicated decision making processes and often left the carer feeling excluded from discussions that have direct implications for their caring role. Assumptions can be made by professionals with regards to decision making ability. Carers also reported increased administrative

"Being consistent and reliable... to inform decision making is difficult. Carers are generous and attentive but administration is cumbersome, inflexible and unresponsive."

– 2020 National Carer Survey respondent

⁸McSherry, B. (2008). Health professional-patient confidentiality: Does the law really matter? *Journal of Law and Medicine*, 15, 489-493.

⁹ Carers NSW (2020). *2020 National Carer Survey: Summary report*. Available online at: <http://www.carersnsw.org.au/research/survey>

burden associated with supported decision making, and increased anxiety around expressing the will and preference of the person they support. Nearly half of the carers who responded to the survey were experiencing high or very high psychological distress.

Moreover, carer respondents who supported a person with disability and who provided cognitive support, had worse outcomes in terms of stress, wellbeing and social connectedness. They also rated the NDIS more poorly, experienced issues with the NDIS at a higher rate, and had a higher unmet support need than those disability carers who do not provide support in decision making. It is important for professionals to consider this when supporting carers who provide decision making support, and to understand what impact this distress may have on a carers capacity to provide decision making support both at that time and into the future.

The Paper notes that certain decisions are required as an NDIS participant transitions through different life stages. This can include a transition from being a child to young adult, from school to employment, or from living at home to living independently. It is important to consider what specific supports are required for these transitions, both to maximise autonomous decision making, and ensure supporters are equipped to provide decision making support. This is particularly important when a participant turns 18. NDIA staff should be sensitive to how this transition impacts on a parent carer who has previously had parental responsibility for their child living with disability. Transitional support should be provided to the participant, and their carer, to support independence.

“The feeling that I am not making the best decisions leads to increased anxiety.”

– 2020 National Carer Survey respondent

The principles of mental capacity clearly stipulate a person’s right to make “unwise” decisions. Carers NSW fully supports that all people have a right to make their own decisions, even where this may not be in the best interest of the individual. However, where a certain decision is likely to adversely impact the rights or safety of a carer, this must be balanced with the notion of dignity of risk. Unlike in the context of a non-caring relationship, where a participant is reliant on a carer to support health and wellbeing, safety and/or independence, carers do not have the same opportunities to remove themselves from the relationship despite the risks posed.

Some decisions may even increase risk of abuse towards carers, a topic rarely broadhed in public discourse. While the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability focused on abuse of people with disability, Carers NSW has heard of many instances where carers have experienced violence or abuse perpetrated by the person they care for, often not intentionally or maliciously, but in many cases linked in some way to a cognitive impairment or mental health condition. This was explored in detail in Carers NSW submission to the Royal Commission on abuse at home.¹⁰ Unintentionally abusive behaviours occurring where a cognitive impairment manifests in behaviours of concern requires a sensitive and nuanced approach to both decision making and safeguarding.

Cognition

Understanding cognition and cognitive ability is at the centre of discussions around mental capacity and decision making. Assessing a person’s capacity to make decisions is, in fact, assessing their cognitive ability to retain, recall, evaluate or weigh up, and appreciate the impacts associated with a specific decision. It encompasses analysis of whether a person can identify and remember the important factors for consideration, and whether they can explore and navigate multiple options or perspectives. This type of assessment is complex, and requires a cognitively supportive workforce which is empathic and protective of the individual rights and needs of decision makers.

¹⁰ Carers NSW (2020). *Disability Royal Commission: Abuse at home*.

Carers NSW is concerned that the Support for Decision Making policy does not adequately address cognition and its role in capacity to make decisions, and therefore does not sufficiently address the complexities around cognitive ability, assessment and support. Carers NSW strongly advocates that further consultation is required, especially to understand the neuropsychological aspects of decision making, to ensure that the workforce is equipped and prepared to carry out holistic and informed assessments of cognitive ability.

Nominee appointments

Goal 4 in the proposed Support for Decision Making policy talks to strengthening the support for decision making approach in the appointment of nominees. Proposed actions include an overhaul of the nominee appointment process, a review of current nominee appointments, and regular review of nominee appointments at plan reviews and significant life stages. The identified indicator of success is an overall reduction in nominee appointments, with particular focus paid to cohorts with disproportionate nominee appointments, however no detail is provided in relation to the process to achieving this goal.

Whilst Carers NSW fully supports a reduction in nominee appointments where this ethically and genuinely supports the maximisation of autonomous decision making capacity for participants, we also strongly advocate that this action should not compromise the rights of participants to nominate one or more carers or other persons to formally support decision making. The proposed actions must also be carried out in a way that supports the participant's outcomes without having adverse implications for their carer or carers.

The consultation paper notes that NDIA data indicates 60% of participants require support with decision making; Carers NSW is concerned for the outcomes of these participants in circumstances where their appointed nominee is removed. Moreover, Carers NSW is concerned that this goal is contrary to common law, within which formal support roles are legislated and recognised as imperative to the safety and wellbeing of people who require such support.

In the context of supported decision making, the NDIS participant remains at the centre, whilst noting that in many circumstances, they will not be the only person affected by the decision. Carers NSW strongly advocates that autonomous decision making and decision making support are not mutually exclusive, and consideration should be given to who is best placed to support the participant to carry out the decision they need or want to make.

The involvement of a supporter can include risk mitigation, building necessary networks where the participant may be isolated without the same networks as others, and building decision making ability rather than taking away the right to make decision. A supporter has the responsibility to respect that the individual has the same rights as others irrespective of their decision making ability.

Carers NSW recognises that only a small cohort of individuals are reliant on substitute decision making, and that this is determined after extensive input from neuropsychology and legal professionals. Depending on their disability and cognitive ability, a person's ability to make an independent decision can be increased through support informally. The more complex a decision, the higher the demands for support can be.

In some cases, a person who retains capacity may simply prefer to delegate to another decision maker or seek their input due to their relationship or expertise. The circumstances surrounding the decision, as well as any individual and relational factors, need to be closely examined. Nominee responsibilities should also be clearly defined, and NDIA staff should be upskilled to examine these factors and enlist support from external professions where this is appropriate.

Reducing the number of nominee appointments will not necessarily constitute improved decision making, and may in fact create risk where this has previously been mitigated.

A focus on maximising decision making ability, with or without the involvement of a nominee will likely be a more strategic goal within the Support for Decision Making policy. Removal of a nominee where this has safeguarding a participant with impaired decision making ability may lead to inconsistencies in the formal and informal care provided, adversely impacting on the wellbeing of the participant. Carers NSW advocates that the extensive information and expertise offered by carers, families and other supporters contributes to better decision making – active involvement of these supporters is therefore imperative.

Consideration must also be given to participants with psychosocial disability who may experience episodic ill-health which impacts on their decision making at that point in time. Carers can be an important safeguard in these instances, and to reduce their involvement at this critical time could have significant consequences.

Carers NSW advocates that the NDIA focus on maximising decision making ability through strengthening of networks, by building the relationships shared between agency staff, participants, carers and families. A collaborative and holistic approach to decision making supports a human rights approach, and upholds the principle of choice and control. Any process embedded within the Scheme to reduce nominee appointments must be accompanied by a clear and simple appeals process to safeguard the rights of participants and their families and carers.

Abuse and undue influence

A paternalistic approach to decision making involves making a decision on behalf of another person, which results in denying a person's human rights and risks the decision not reflecting a person's will and preference. Sometimes this approach is taken unintentionally, or may be the direct result of ill-intent. Representing another person's views can be highly complex and challenging, and carers report that professionals can make assumptions around ill-intent that are incorrect or unfounded. A lack of adequate information about the decision at hand and the decision making process can confuse perspectives and roles, therefore it is important that all parties have the information they require.

Where genuine and substantiated concerns regarding risk of abuse are present, or there are concerns about ill-intent or coercive control, it is imperative that NDIA staff are competent in assessing those concerns through a safeguarding lens. Given that the NDIA is not an investigative or emergency service, onward referral to the appropriate services should also be fully considered, and this process should be streamlined.

Sometimes the decision making limitations of a person living with cognitive impairment are not recognised by professionals, especially where the person exhibits strong cognitive abilities in other areas such as communication or memory. This often increases the risk of exposure to undue influence and exploitation of people with impaired capacity. In some cases, professionals can mistake the expression of a preference with autonomous decision making capabilities, reflecting a lack of expertise and limited understanding of the complexities associated with cognition and decision making. Carers NSW believes that additional training for NDIA staff is required to prevent this and to reduce the potential risk of abuse or exploitation of persons with disability.

Cultural considerations

Carers NSW also wishes to emphasise the importance of understanding how linguistic and cultural barriers can complicate decision making for culturally and linguistically diverse (CALD) participants and carers. Sufficient support with language translation should be provided to participants for whom English is a second language, and families and carers should not be relied upon for such support.

Cultural definitions and understanding of capacity, disability, family and care differ amongst diverse groups, including CALD and Aboriginal and Torres Strait Islander peoples. Historical experiences must also be taken into account when working with Aboriginal and Torres Strait Islander participants, families and carers, to ensure their decision making rights are supported through culturally sensitive practice.

Conclusion

Carers NSW advocates that autonomous decision making for participants and consideration of carers' needs in the decision making context need not be mutually exclusive. Carers NSW believes that the new NDIS Support for Decision Making policy should uphold and ensure the rights of participants and their carers in decision making processes, acknowledging the important role and expertise of carers in supporting people with disability. Continued consultation with participants and their supporters is imperative to ensuring that the Support for Decision Making policy reflects the views of those who are supported by the Scheme.