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Supporting Choice and Control—An Analysis of the Approach Taken to Legal Capacity in Australia’s National Disability Insurance Scheme

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Abstract: In mid-2013, the Australian federal government introduced the National Disability Insurance Scheme (NDIS), a ground-breaking reform of disability support services, encapsulated by the mantra of increasing “choice and control”. The scheme provides eligible persons with disabilities a legislated entitlement to supports they may require to increase their independence and social and economic participation. The NDIS has been hailed as a major step forward in Australia’s efforts to realize the human rights of persons with disabilities, in accordance with the UN Convention on the Rights of Persons with Disabilities (CRPD). A core aspect of the CRPD is guaranteeing persons with disabilities their civil and political right to equality before the law, including their right to enjoy legal capacity on an equal basis with others, as provided by Article 12 of the CRPD. The purpose of this paper is to examine how the concept of choice and control has been operationalized within the NDIS and to critically analyze the extent to which it accords with the requirements of Article 12. It will be argued that even though the NDIS expressly seeks to implement the CRPD as one of its key objectives, it ultimately falls short in fully embracing the obligations of Article 12 and the notions of autonomy and personhood underlying it.

Keywords: disability; NDIS; choice and control; autonomy; Convention on the Rights of Persons with Disabilities; legal capacity; Article 12; supported decision-making; supports; General Comment No. 1

1. Introduction

For the first time in Australia, the primary goal of the federal government’s disability policy is to advance the independence and personal autonomy of persons with disabilities—symbolized by the mantra of increasing “choice and control”. This is being implemented in large part through the National Disability Insurance Scheme (NDIS), which provides eligible persons with disabilities a legislated entitlement to reasonable and necessary supports to assist them in increasing their independence and social and economic participation.

This article will examine how the notion of choice and control has been operationalized within the NDIS framework and critically analyze this against the requirements of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) adopted in 2006. It will demonstrate that whilst the NDIS seeks to promote individual autonomy and champion the provision of support, it still permits a substituted decision-making model for the exercise of legal capacity via the appointment of nominees. This has led to a situation where the need for supports in enabling the social and economic participation of persons with disabilities is embraced, yet the need for support in exercising legal capacity throughout the NDIS process, to access and manage these participatory supports, is largely absent. It will be argued that this incongruent reality stems from competing conceptions of personal

autonomy and human flourishing underlying the NDIS, which must be resolved to properly ground a support paradigm within the NDIS that is consistent with the CRPD.

The article will be structured as follows: Section 2 will provide a theoretical framework for the analysis, examining notions of personhood and summarizing the requirements of Article 12 of the CRPD in respect of legal capacity; Section 3 will summarize legal capacity laws and reform efforts in Australia, and provide an overview of the NDIS and its approach to legal capacity and the provision of support in exercising legal capacity; Section 4 will then critically analyze the approach of the NDIS to legal capacity and examine its compatibility with Article 12 of the CRPD; and Section 5 will provide some high-level recommendations to guide the reform efforts needed to better align the NDIS with Article 12.

2. Theoretical Framework

2.1. Overview of Article 12

Article 12 of the CRPD recognizes a right to legal capacity for all persons with disabilities, on an equal basis with others. Underpinning this article is the core human right of equal recognition before the law, which includes the right to be a full legal person—a subject with rights and responsibilities. In order to be a full legal person, an individual must be able to hold rights (legal status) and exercise these rights (legal agency). Together, these elements make up legal capacity, a mechanism by which rights and responsibilities are granted or denied to an individual ([Committee on the Rights of Persons with Disabilities 2014](#), paras. 11–12).

Legal capacity has been described as a tool that helps to advance and ‘secure notions of personhood in the lifeworld’ ([Quinn 2010](#), p. 3). Article 12 adopts a conceptualization of personhood that is inclusive and holistic, moving away from a reverence to cognition and rationality and towards a more ‘three-dimensional view of the human condition’ ([Quinn and Arstein-Kerslake 2010](#), p. 38). It sees autonomy as a relational dynamic, which is manifested through ‘relations of support, advocacy, and enablement’ ([Davy 2015](#), p. 132). It recognizes that persons are socially embedded and personhood is shared.

From this basis, the core normative principles underpinning Article 12 are that: (a) legal capacity is a universal attribute inherent in all persons; (b) legal capacity and mental capacity are two distinct concepts that should not be conflated. Mental capacity is an individual’s decision-making ability, which can vary based on a range of factors. Legal capacity is the legal recognition of legal status and legal agency; and (c) States Parties (States) must never deny, remove or restrict a person’s legal capacity on the basis of disability or their level of decision-making capability ([Committee on the Rights of Persons with Disabilities 2014](#), paras. 8 and 15; [Flynn and Arstein-Kerslake 2014](#), p. 88).

Substituted decision-making regimes represents a denial of legal capacity on the basis of disability and infringes all three principles. Substituted decision-making regimes exist if any one or more of these factors are present: (a) an individual’s legal capacity can be removed; (b) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and/or (c) any decision can be based on an objective best interests assessment ([Committee on the Rights of Persons with Disabilities 2014](#), para. 27).

In instances where it is not practicable to determine the will and preferences of a person, after significant efforts have been made (often referred to as the “hard cases”), any determinations must be made on the basis of the “best interpretation” of a person’s will and preferences and not an objective best interests test ([Committee on the Rights of Persons with Disabilities 2014](#), para. 21; [Arstein-Kerslake and Flynn 2016](#), p. 477–78).

2.2. The Need for Support

As well as requiring recognition of equal legal capacity, Article 12 expressly acknowledges that some persons with disabilities may require assistance to exercise their legal capacity. Article 12.3 of

the CRPD mandates that States ‘shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity’. This provision is the key to giving effect to the paradigm shift envisioned by Article 12 (Quinn 2010, p. 21). It deliberately embraces the relational model of autonomy and shifts towards a support paradigm that seeks to augment decision-making capacities rather than displacing legal capacity at the first sign of reduced decision-making abilities (Quinn and Arstein-Kerslake 2010, pp. 47–48).

Support refers to a broad cluster of ‘both informal and formal support arrangements, of varying types and intensity’ (Committee on the Rights of Persons with Disabilities 2014, para. 17). It includes formal legally-recognized supported decision-making arrangements, where an individual appoints one or more persons to assist them to: ‘(a) obtain and understand information, (b) evaluate the possible alternatives and consequences of a decision, (c) express and communicate a decision, and/or (d) implement a decision.’ (Special rapporteur on the rights of persons with disabilities 2017, para. 41.) It also includes less formal support such as advocacy, peer support, personal assistance, and networks of supports including family, friends and professionals, which may provide a broad range of supports including support for communication, access to information, and personal planning (Gooding 2015, p. 50; Special rapporteur on the rights of persons with disabilities 2017, para. 54). Regardless of the formality, the nature and intensity of supports should be individually designed to adapt to differing levels of abilities and to be both culturally and situationally appropriate (Committee on the Rights of Persons with Disabilities 2014; Arstein-Kerslake 2017, p. 72).

Support systems and practices are building blocks of all social networks. As explained by the Special Rapporteur on the rights of persons with disabilities, ‘[e]veryone needs support from others at some stage, if not throughout their life, to participate in society and live with dignity. Being a recipient of support and offering support to others are roles we all share as part of our human experience, regardless of impairment, age or social status.’ (Special rapporteur on the rights of persons with disabilities 2016, para. 13.) The need for States to provide persons with disabilities with access to supports arises from the fact that social designs have not naturally integrated the supports required by persons with disabilities, particularly persons with intellectual disabilities, autistic persons and persons with dementia. Rather, social designs include numerous exclusory social practices and discourses for persons with disabilities. This includes requirements for particular types and modes of communication and methods of cognitive functioning to fully participate in society (Special rapporteur on the rights of persons with disabilities 2016, paras. 13 and 16; Arstein-Kerslake and Flynn 2017, p. 22). From this recognition flows the conclusion that, in order to ensure persons with disabilities are fully and effectively included in society, States are obliged to dismantle these exclusionary practices and fully integrate the supports persons with disabilities require into its social design. This is essential for the purpose of the CRPD¹ to be achieved, with access to supports very often being a precondition for persons with disabilities being able to enjoy and exercise their human rights on an equal basis with others. Further, while recognizing legal capacity on an equal basis with others may satisfy formal equality requirements, ensuring this is supplemented with access to supports—so persons with disabilities not only have the full and equal legal right to make decisions, but also the necessary support to do so in practice—is needed for inclusive equality².

This reasoning aligns with recent developments in social contract theory. Wong has convincingly argued that all persons require “enabling conditions” to develop and exercise the two moral powers necessary to participate in Rawls’ social contract—capacity for a sense of justice and capacity for a conception of the good (Wong 2009). Flynn and Arstein-Kerslake build on Wong’s approach and argue that enabling conditions include a continuum of support for the exercise of legal capacity (Flynn and

¹ To promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (CRPD art 1).

² For an explanation of inclusive equality, see General Comment No. 6 (2018) on equality and non-discrimination (26 April 2018) CRPD/C/GC/6 para 11 by the Committee on the Rights of Persons with Disabilities.

[Arstein-Kerslake 2014](#)). This is because receiving support is a precondition to persons with disabilities being able to exercise Rawls' basic rights and liberties and therefore participate in the social contract.

2.3. Implementation of Article 12.3

As the right to equality before the law is a civil and political right, the rights provided for in Article 12 are immediately realizable. The Committee on the Rights of Persons with Disabilities (CRPD Committee) stated in its General Comment No. 1 on legal capacity that the 'State obligation, provided for in Article 12, Paragraph 3, to provide access to support in the exercise of legal capacity is an obligation for the fulfilment of the civil and political right to equal recognition before the law' (2016, para. 30) and the lower standard of progressive realization does not apply.

Accordingly, States must immediately begin taking steps to provide access to supports that persons with disabilities may need to exercise their legal capacity ([Committee on the Rights of Persons with Disabilities 2014](#), para. 30). States' obligations in this respect are absolute and not limited by any qualifiers such as proportionately which applies in the case of reasonable accommodation duties. Rather, support arrangements must be 'available, accessible, adequate and affordable' ([Special rapporteur on the rights of persons with disabilities 2016](#), paras. 48–56). This means, inter alia, creating a support paradigm that provides all persons with disabilities with access to the fullest range of supports, at nominal or no cost and facilitates the creation of support, particularly for those that are socially isolated ([Special rapporteur on the rights of persons with disabilities 2017](#), para. 29; [Committee on the Rights of Persons with Disabilities 2014](#), para. 29).

The nature and parameters of such support paradigms are still developing, both normatively and in practice. The CRPD Committee and academics have put forth some core, guiding principles to assist States in developing appropriate support frameworks—these are: (1) respect for the rights, will and preferences of persons with disabilities (CRPD Article 12.4); (2) a human rights based-approach, consistent with the general principles of the CRPD and the protection of all human rights; (3) recognition that support can never be imposed, it must be at the complete discretion of the individual and therefore can always be refused, terminated or amended; (4) any assessment procedures used in determining the provision of support must be non-discriminatory and focused on supporting the individual in augmenting their decision-making ability, rather than assessing the mental capacity of an individual. A strengths rather than a deficits approach should be adopted; and (5) the provision of support must always be tailored to the specific needs of the individual ([Committee on the Rights of Persons with Disabilities 2014](#); [Special rapporteur on the rights of persons with disabilities 2017](#); [Arstein-Kerslake 2017](#)). States breach their obligations under Article 12 if they design and implement a support model 'in parallel with the maintenance of substitute decision-making regimes' ([Committee on the Rights of Persons with Disabilities 2014](#), para. 27). Such regimes represent a discriminatory denial of legal capacity on the basis of disability and ignore the universal nature of legal capacity. The CRPD Committee has stated that substituted decision-making regimes must be immediately abolished and replaced with a system of supports for the exercise of legal capacity ([Committee on the Rights of Persons with Disabilities 2014](#), paras. 17, 25 and 26).

3. Australia, Legal Capacity and the NDIS

3.1. Overview of Legal Capacity Laws and Reform Proposals in Australia

Legal capacity is a foundational concept in Australian law. Historically, legal capacity has been regulated primarily at the state and territory level (Australian Law Reform Commission (ALRC) 2014, para. 10.5). These jurisdictions all have guardianship regimes, premised on a least restrictive approach, which seeks to maintain the person's legal capacity to the "greatest extent possible" ([Bigby et al. 2017](#), p. 223). In addition to state and territory laws, Commonwealth (federal) laws apply to many areas which legal capacity is relevant. This includes contract law, marriage and voting. Commonwealth

laws are also increasingly relevant per the federal government's external affairs power to implement its obligations under international treaties (Australian Constitution s. 51(xxix)).

It was pursuant to this power that the Australian federal government ratified the CRPD in July 2008. Australia's ratification was subject to three interpretive declarations, one of which related to legal capacity. It provided that Australia understood that the CRPD allowed for substituted decision-making where necessary, as a last resort and subject to safeguards (United Nations 2009). An interpretive declaration of this nature 'purports to clarify the meaning or scope of treaty provisions, and outlines a state's understanding of its obligations, without purporting to exclude or modify its legal effects' (Alston 2017, p. 27). Since the publication of General Comment No. 1 in 2014, it is evident that this interpretation is inconsistent with the CRPD Committee's interpretation of Article 12. General Comments, while not strictly legally binding, are highly authoritative. Accordingly, retaining substitute decision-making means Australia is in breach of Article 12, as understood by the CRPD Committee, irrespective of the interpretative declaration. The CRPD Committee has called on Australia to withdraw all its interpretative declarations, including in respect of legal capacity (Committee on the Rights of Persons with Disabilities 2013).

Following ratification, the Australian Law Reform Commission (ALRC) was asked by the federal government to conduct a comprehensive inquiry into 'the laws and legal frameworks within the Commonwealth jurisdiction that deny or diminish the equal recognition of people with disability as persons before the law and their ability to exercise legal capacity' (Australian Law Reform Commission 2014). Following the inquiry, the ALRC developed a set of National Supported Decision-Making Principles in order to guide the reform of all Commonwealth, state and territory laws relating to decision making. The National Decision-Making Principles are:

1. Equal rights: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. Support: Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
3. Will, preferences and rights: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
4. Safeguards: Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

These National Decision-Making Principles are consistent with Article 12 of the CRPD and the core principles underpinning it. While a full analysis of the ALRC's recommendations is beyond the scope of this paper, it must be noted that the recommendations include a representative model for decision-making, not explicitly referenced in the four general principles. This model allows for a decision-maker to be appointed by a third party, as a measure of last resort, where a 'person needs a representative but is unable to request appointment themselves, even with support' (Australian Law Reform Commission 2014, para. 4.101). This will be analyzed in Section 5.

Since the 2014 Report, a number of states and territories have commenced law reform efforts, with varying levels of consistency with the ALRC's recommendations. However, to date, there has been no legal reform, at the Commonwealth or state and territory level, affording support in the exercise of legal capacity widespread legal status.³

³ Note that there have been some legislative developments in Victoria and South Australia which provide or encourage support in limited circumstances. For further details see (Carney 2017).

3.2. NDIS and Its Approach to Legal Capacity

3.2.1. Overview of the NDIS

In mid-2013, the NDIS was introduced in Australia—a new national scheme governing the way governments provide funding for the supports persons with disabilities may need. It represents one of the most significant social and economic policy reforms in Australia in recent times. The overarching vision of the NDIS is to ‘optimise the social and economic independence and full participation of people with disability’ (NDIS Act, s. 4(2)). A core aspect of achieving this vision is adopting a person-centered approach to the provision and funding of support for certain eligible persons with disabilities, where individuals exercise choice and control over the services and support they receive.

The design of the NDIS draws on human rights principles and approaches. Indeed, the first stated object of the legislation establishing the NDIS is to, in conjunction with other laws, give effect to Australia’s obligations under the CRPD (s. 3(1)(a)). Other objects of the Act reflect approaches and principles of the CRPD, including to ‘support the independence and social and economic participation of people with disability’ (s. 3(1)(c)) and ‘enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports’ (s. 3(1)(e)). Further, Section 3(3)(c)(1) states that, in giving effect to the objects of the NDIS Act, regard is to be had (amongst other matters) to ‘the broad context of disability reform provided for in . . . the National Disability Strategy 2010–2020’. This strategy explicitly adopts the core principles of the CRPD as set out in Article 3. However, the objects on the NDIS Act are not exclusively focussed on implementing Australia’s human rights obligations. Rather, the NDIS Act leavens this objective with economic considerations. The Act provides that its objects are to be achieved by ‘adopting an insurance-based approach, informed by actuarial analysis, to the provision and funding of supports for people with disability’ (s. 3(2)(b)) and that, in giving effect to the objects, regard must be had to ‘the need to ensure the financial sustainability of the National Disability Insurance Scheme’.

The central pillar of the NDIS is an individual budget model for the funding of disability supports. It provides eligible participants with a legislated entitlement to individualised disability supports to assist them in pursuing their goals, live independently, and be included in the community as fully participating citizens (NDIS Act s. 4(11)). This is provided through an individualised support package (referred to in this article as a “NDIS package”), which is tailored to an individual’s goals and support needs. Under a NDIS package, a person with a disability directly receives funds to purchase services and supports they choose from the market.

A person with disability is eligible for a NDIS package if they meet three criteria: (1) a residence requirement: a person must reside in Australia and either be an Australian citizen or hold a specified visa (NDIS Act s. 23); (2) an age requirement: a person must, at the time of applying to become a participant, be under 65 years of age (NDIS Act s. 22); and (3) either a disability requirement which requires a person to establish they have a permanent and significant impairment(s) that substantially reduces their functional capacity or psychological functioning⁴ (NDIS Act s. 24) or an early intervention requirement, which exists if a child or adult could benefit from intervention to alleviate the impact of their impairment upon their functional capacity by providing support at the earliest possible stage (NDIS Act s. 25).

The National Disability Insurance Agency (NDIA), the independent statutory agency tasked with implementing the NDIS, estimates that there will be approximately 460,000 people eligible for an individualised support package, representing approximately 10% of all persons with disabilities in Australia ([Disabled People’s Organisations Australia 2017](#)).

Once an individual establishes that he or she is eligible for a NDIS package, they become a “NDIS participant”. To gain access to funding, a participant must prepare an individualised personal support

⁴ Note that the disability requirement is largely based on the medical model of disability.

plan—often referred to as a “NDIS plan”—to outline their goals and aspirations and NDIS support requirements. The NDIA is tasked with facilitating the preparation of a participant’s plan (NDIS Act s. 32(1)). This process includes a planning meeting between the participant and NDIA planners, where the participant may be joined by family, carers, or other significant persons. A participant’s final, approved NDIS plan includes a statement of participant supports, which outlines the type of supports covered by the plan and the amount of funding to be provided for each support area. (NDIA 2018b).

NDIS supports are categorized as either “general” supports or “reasonable and necessary” supports. General supports are supports provided by the NDIA that are in the nature of a coordination, strategic or referral services or activities (NDIS Act s. 13(2)). Reasonable and necessary supports are more substantive and must:

- assist the participant to pursue their goals, objectives and aspirations and maximize their independence;
- assist the participant to undertake activities, so as to facilitate social and economic participation, including to:
 - support the participant to live independently and to be included in the community as fully participating citizens; and
 - enable them to participate in the mainstream community and in employment;
- represent value for money in that the costs are reasonable relative to both the benefits achieved and the cost of alternative support;
- takes account of what is reasonable to expect from families, carers, informal networks and the community to provide; and
- be most appropriately funded or provided through the NDIS, (NDIS Act ss. 4(11) and 34).

Reasonable and necessary supports may be in a range of areas, including employment, social participation, independence and living arrangements (NDIS Act s. 33(1)(a)). Once a support is deemed to be reasonable and necessary, it must be fully funded.⁵ In this article, general supports and reasonable and necessary supports that may be funded under a NDIS package, as opposed to supports relevant to exercise of legal capacity, will be referred to as “NDIS supports”.

Once a NDIS plan is finalized and approved by the NDIA, the NDIS funding specified in the plan can be managed via three different methods: (1) self-management, where the participant manages their NDIS funds; (2) plan-management, where a nominee or plan management provider manages a participant’s NDIS funds; or (3) NDIA management, where the NDIA manages a participant’s NDIS funds on their behalf. Regardless of the form of management, NDIS funds must be used to purchase disability services and supports from providers in the market. NDIS plans are approved for a period of up to two years, after which time a participant’s plan is reviewed and updated and consequential changes made to the participant’s NDIS package (NDIA 2018b).

Throughout this article, the various steps involved in gaining access to, planning, managing and reviewing a NDIS package will be referred to as the “NDIS process”.

For the 90% of persons with disabilities who are not eligible for an individualised support package, the NDIS provides assistance through: (a) information, linkages and referrals to connect persons with disabilities, their families and carers, with broader systems of support and mainstream services, such as health, education and transport; and (b) facilitating capacity building supports for persons with disabilities, their families and carers. This stream of the NDIS is referred to as Information, Linkages and Capacity (ILC). It is implemented through a grant process to organizations in the community, rather than direct funding to individuals.

⁵ Recently confirmed in *McGarrigle v National Disability Insurance Agency* [2017] FCA 308, [94].

Once the NDIS is fully rolled out across Australia, it is estimated that it will cost around \$22 billion in the first year of full operation (2019–2020), which is projected to be approximately 0.9% of the gross domestic product at 2020 (NDIA 2018a).

3.2.2. Approach of the NDIS to Legal Capacity and Decision-Making Supports

The role and participation of persons with disabilities in the NDIS process is governed by the following key general principles provided by the NDIS Act:

1. 'People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports.' (s. 4(4)).
2. 'People with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives.
3. People with disability will be supported in their dealings and communications with the Agency so that their capacity to exercise choice and control is maximized.
4. The National Disability Insurance Scheme is to:
 - a. respect the interests of people with disability in exercising choice and control . . . ;
 - b. enable people with disability to make decisions that will affect their lives, to the extent of their capacity; and
 - c. support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.' (s. 17(A)).
5. '[t]he preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable: (a) be individualised; and (b) be directed by the participant . . . ' (s. 31).

It is evident from these principles that there is a strong presumption in favor of persons with disabilities having and exercising legal capacity. However, the approach of framing the recognition of legal capacity as a presumption gives rise to difficulties, which will be analyzed in Section 4.2 below.

The need for support is also clearly envisaged in the principles. However, there are limited provisions in the NDIS Act, which build on these principles and govern how this support is to be provided or regulated in practice. There is no recognition of, or framework for, supported decision-making throughout the NDIS process. Instead the NDIS Act dedicates Part 5 of the Act to establishing a nominee scheme.

This scheme provides for two types of nominee—a correspondence nominee and a plan nominee. The role of a correspondence nominee is narrow and relates to receiving notices from, or making requests of, the NDIA on behalf of a participant (NDIS Act s. 39; [Nominee Rules rr 3.9 and 3.10](#)). The role of a plan nominee is much broader; he or she may prepare, review or replace a participant's NDIS plan and/or manage the funding under a NDIS package (NDIS Act s. 78). Either type of nominee can be appointed at the request of a participant or on the initiative of the Chief Executive Officer of the NDIA (CEO) (NDIS Act ss. 86, 88).

There are a number of rules that govern the circumstances under which the CEO can appoint a nominee and who can be appointed, which intend to limit occurrences of such appointments (NDIS Act s. 88; [Nominee Rules rr. 3.3, 3.4, 3.14, 4.6–4.7](#)). For example, the [Nominee Rules](#) provides that the appointment of a nominee by the CEO is justified only 'when it is not possible for participants to be assisted to make decisions for themselves' (r. 3.3). If the CEO decides that a nominee should be appointed, there are a range of matters which he or she must consider in deciding who to appoint (rr. 4.6–4.7). The CEO must have regard to any existing legal decision-making arrangements under Commonwealth, state or territory laws (including guardianships, powers of attorney and advanced health directives) in deciding whether to appoint a NDIS nominee and if so who to appoint (NDIS Act s.

88(4); Nominee Rules rr. 3.14(b)(iii), 3.14(v)(c), 4.6(c), 4.8(a), 4.10(d), 4.12). The CEO can either appoint a nominee for a specified period of time or indefinitely (Nominee Rules rr. 4.9–4.11).

Where a nominee is appointed upon a participant's request, the participant may ask that the appointment be cancelled at any time and this must be respected (NDIS Act s. 89; Nominee Rules pt. 6). This is not the case where a nominee is appointed on the initiative of the CEO (NDIS Act s. 90; Nominee Rules pt. 6). A number of duties are imposed on a nominee when conducting their role (NDIS Act s. 80; Nominee Rules rr. 5.3, 5.4). A nominee appointed by the CEO is only permitted to conduct his or her role in instances where the nominee considers that the participant cannot do the act in question (Nominee Rules r. 5.5).

Separate to the nominee scheme, the NDIA is also able to deny the participant the ability to self-manage their funds if the CEO considers that the management of the plan would present an 'unreasonable risk to the participant' (NDIS Act s. 44; Plan Management Rules Part 3). The Plan Management Rules provide that, in deciding if there is an unreasonable risk, the CEO must consider a range of factors including the capacity of the participant to manage finances, the ability of the person to make decisions, the vulnerability of the participant, and whether material harm, including material financial harm, could result from the participant managing his or her funding (r. 3.8).

4. Analysis of the Approach Taken to Legal Capacity in the NDIS Process

4.1. Applicability of Article 12

The NDIS process involves a number of individual-led steps, from proving eligibility, to preparing a NDIS plan, to managing and using the funds to access the supports required. Throughout these various steps, a number of decisions must be made, which represent 'major life course shaping decisions' (Carney 2015, p. 49). The decisions will affect whether an individual receives a NDIS package, how much funding is received under it, and how the funds are managed.

These decisions are legal in nature. They necessarily involve engaging with the requirements of the NDIS Act and an individual's decision-making throughout the NDIS process has clear legal implications. It therefore involves exercising legal agency (Arstein-Kerslake 2017). Article 12 is therefore enlivened and Australia is obliged under the CRPD to provide access to supports that persons with disabilities may need in exercising their legal capacity throughout the NDIS process. However, the NDIS Act falls short in providing this access in a number of inter-related respects. These will be considered in turn below.

4.2. Shortcomings of the Approach Taken to Legal Capacity in the NDIS Process

4.2.1. Nominee Scheme

The nominee scheme amounts to a substituted decision-making regime for three reasons. First, both a correspondence and plan nominee can be appointed on the initiative of the CEO of the NDIA. While the CEO must consider the wishes of the NDIS participant (in deciding whether to appoint a nominee and whom to appoint), these wishes are not paramount or binding. This allows for a decision-maker to be appointed by someone other than the individual NDIS participant themselves. Further, the participant cannot unilaterally cancel the appointment. This is contrary to recognition of legal capacity as a universal attribute of all persons, that cannot be restricted or denied via the appointment of a substituted decision-maker against the person's will.

Second, decisions made by a plan nominee, whether appointed by the CEO of the NDIA or the individual participant, need not be based solely on the will and preferences of the participant. Rather, a nominee has a duty to: '(a) ascertain the wishes of the participant; and (b) act in a manner that promotes the personal and social wellbeing of the participant.' (Nominee Rules r. 5.3.). It is not clear if the phrase "wishes" is intended to be synonymous with "will and preferences". In any event, a nominee need not act strictly in accordance with the wishes of the participant under (a), and (b)

provides scope for an objective best interest determination to guide the nominee's decisions. The use of a best interest test in respect of adults with disabilities does not comply with Article 12 ([Committee on the Rights of Persons with Disabilities 2014](#), paras. 21 and 27). This is because it allows a third party to impose a decision on an individual based on an objective view of what is in their best interests. It is therefore contrary to the States' ensuring that measures relating to the exercise of legal capacity always respect the individual's rights, will and preferences (as required by Article 12.4). While it would be entirely permissible under Article 12 for an individual to appoint a plan nominee, if they wished to delegate their decision-making in the NDIS process to a trusted person, any decisions made by the plan nominee would have to be solely based on the will and preferences of the participant.

Finally, in instances where a plan nominee is appointed, a participant's ability to exercise his or her legal capacity in respect of decisions to be made throughout the NDIS process is removed. While a plan nominee appointed by a CEO is only permitted to act on behalf of the participant *if* the participant is "not capable" of doing the act in question (Nominee Rules r. 5.5), whether this is the case is determined by the nominee themselves without consideration of the potential role of supports in assisting the person to do the act in question. These provisions are again contrary to Article 12 and its recognition that legal capacity is a universal attribute that cannot be denied, removed or restricted on the basis of disability or decision-making abilities.

Accordingly, all three elements of the CRPD Committee's definition of substituted decision-making regimes (set out above in Section 2.1) are present in the case of plan nominees. The second element—that a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will—is present in the case of correspondence nominees.

As a substituted decision-making regime, the nominee scheme is contrary to Article 12 and the right of all persons with a disability to enjoy legal capacity on an equal basis with others. The denial of legal capacity that the nominee scheme permits will have a direct impact on the ability of persons with disabilities in Australia to exercise choice and control over the NDIS supports they receive and will increase the likelihood of support services being imposed that are contrary to their dignity and rights ([Special rapporteur on the rights of persons with disabilities 2016](#), para. 55). Not only is this contrary to Article 12 of the CRPD, it is also contrary to the objectives of the NDIS itself.

Reports from on the ground suggest that the NDIA may not be frequently using the nominee scheme. Rather, state and territory-based guardianship and other substituted decision-making regimes are relied upon ([Office of the Public Advocate 2017](#)). While a full analysis of these state and territory-based regimes and how they compare to the nominee scheme is beyond the scope of the paper, it should be noted that the NDIS nominee provisions 'outstrip their state and territory counterparts in terms of their decision-making guidelines' ([Carney 2015](#), p. 50). The NDIA does not report on the number of nominees appointed in their quarterly or annual reports, so it is difficult to verify whether it is correct that the nominee scheme is rarely being used by the NDIA. A first step in any reform efforts should be quantifying and reporting on the NDIA's use of the nominee scheme. Further, it would be useful to gather the reflections of NDIA staff on the use (or lack therefore) of the nominee scheme. A lack of reliance on the scheme by the NDIA may be indicative of the scheme not aligning with the new paradigm they are tasked with implementing.

In any event, the potential lack of use of the nominee scheme should not preclude analysis or reform of it. To the contrary, now is the opportune time to critically review and replace the nominee scheme before there is any further uptake and to pre-empt arguments that it should be relied upon more as a better alternative to state and territory-based guardianship arrangements. NDIS participants deserve better than the least restrictive option; they have a right to access supports to exercise their legal capacity in the context of the NDIS, and the NDIS Act should establish a framework to provide for this.

4.2.2. Restrictions on the Ability to Choose to Self-Manage Funds

Separate to the nominee scheme, the ability of the CEO to deem that a participant cannot self-manage their own funds also amounts to substituted decision-making being permitted, as a participant's legal capacity can be removed in relation to his or her decision as to how to manage their funds. As stated by the CRPD Committee, a system amounts to a substituted decision-making regime if legal capacity is removed from a person, even if this is in respect of single decision ([Committee on the Rights of Persons with Disabilities 2014](#), para. 27)

The inclusion of a mechanism whereby the NDIA's CEO can restrict the ability of an individual to choose to self-manage their NDIS funds—funds which they are legally entitled to as a NDIS participant—on the basis of an assessment of risk (considering factors including ability to make decisions, capacity to manage funds and “vulnerability”), reflects a conflation of the concepts of mental capacity and legal capacity. While a person's ability to manage their NDIS funds may vary based on a range of factors, this does not diminish their right to legal capacity in this respect. It also reflects a discriminatory denial of legal capacity on the basis of disability. Similar mechanisms do not exist for other government funding that is not specifically for persons with disabilities. Any restrictions of legal capacity on the basis of serious risk should only be permitted in the rarest of cases, and any State interventions must be applied equally (in both purpose and effect) to people with and without disabilities ([Committee on the Rights of Persons with Disabilities 2014](#), para. 13; [Arstein-Kerslake and Flynn 2016](#), p. 483). It is questionable if a financial risk can ever amount to a sufficiently serious risk of harm to justify State intervention.

Rather than relying on such discriminatory assessment of risk mechanisms, the focus should instead be on providing access to the support participants may need to self-manage their funds, if they wish to self-manage their NDIS funds. A support model seeks to restore the “dignity of risk” to persons with disabilities, including in respect of managing funding provided by the State. While safeguards to prevent abuse, exploitation and undue influence are necessary, these must be based on the central principle of respect for a will and preferences. This is currently not reflected in the NDIS assessment of risk provisions.

Again, it is difficult to ascertain the extent to which the NDIA is restricting the ability of participants to self-manage their funds and more transparent reporting and collection of data is required.

4.2.3. Qualified Recognition of Equal Legal Capacity

The third major shortcoming of the approach adopted to legal capacity in the NDIS process is the qualified language used throughout the NDIS Act when discussing the legal capacity of persons with disabilities. For example, one of the general principles of the NDIS is that:

‘People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.’ (s. 4(8)) (emphasis added).

While this general principle seeks to recognize that persons with disabilities enjoy legal capacity on an equal basis with others, it curtails this recognition by specifying it is ‘to the full extent of their capacity’. This conflates legal capacity and mental capacity⁶ and implies that the right of persons with disabilities to enjoy and exercise their legal capacity in the NDIS process is proportionate to their decision-making abilities. Separately, the language of best interests, rather than will and preferences, is problematic, as is the phrase “equal partners in decisions”. It is unlikely this type of language would

⁶ The provision does not specify *mental* capacity, but the provision is concerning an individual's ability to make decisions. Throughout the NDIS Act, “capacity” is used interchangeably to refer to both mental capacity and legal capacity. This is emblematic of the conflation of the concepts.

be used in the case of persons without disability and its use here indicates that the right of persons with disabilities to equal recognition before the law, including the right to universal legal capacity, is not fully recognized.

In relation to the NDIS process, the NDIS Act provides that ‘people with disability are assumed, *so far as is reasonable in the circumstances*, to have capacity to determine their own best interests and make decisions that affect their own lives’ (emphasis added) (NDIS Act s. 17 (A) (1)). The framing of the provision as an assumption and the caveat of “so far as is reasonable in the circumstances” allows, indeed pre-empts, circumstances where it would be “reasonable” to question the legal capacity⁷ of some individuals with disabilities and potentially restrict or deny it. Other forms of conditional language are also used throughout the NDIS Act, such as “where possible” and “so far as reasonably practicable”, to allow for the legal capacity of persons with disabilities to be restricted on the basis of decision-making abilities.

The use of such qualifications and presumptions is contrary to Article 12. The right to legal capacity is universal. While decision-making capacity may vary, this does not in any way diminish legal capacity. Every individual has a right to be recognized and respected as a full legal person, with rights, responsibilities and agency. It is never reasonable to question an individual’s right to be recognized as a full legal person, and to enjoy legal capacity on an equal basis with others, based on a person’s perceived or actual decision-making abilities. As such, full legal capacity must be recognized in the NDIS Act as a right of all persons with disabilities, rather than as an assumption that can be overturned. From this basis, the focus should be on providing access to decision-making supports that persons with disabilities may need to augment decision-making capacity and exercise their legal capacity. At present, this is largely absent from the NDIS Act and this represents the final shortcoming.

4.2.4. Lack of a Decision-Making Supports Regime

The NDIS Act does not establish a decision-making support regime. While the need for support to augment decision-making abilities is recognized, this is not backed-up with a framework to guide what form this support may take, how it can be accessed, how it is regulated and in what ways it can be funded.

The absence of a comprehensive decision-making supports regime is problematic for a number of reasons, not least because of the highly individualised, self-directed nature of the NDIS. The entire scheme, like any insurance scheme, relies heavily on a ‘process of self-activation’. Each step along the NDIS process, from accessing the scheme to finding appropriate service providers, are ‘highly demanding cognitive and administrative tasks’ (Soldatic et al. 2014, p. 12), which place a ‘considerable burden on individuals to negotiate the best outcome possible for themselves’ (Davy 2017, p. 219).

The NDIS Act also does not seek to facilitate the creation of supports ‘for people who are isolated and may not have naturally occurring supports in the community’ ((Committee on the Rights of Persons with Disabilities 2014, para. 29(d))). The failure to do this runs the risk of creating new hierarchies and inequalities amongst persons with disabilities. To engage many potential NDIS participants in marginalized groups will require significant out-reach and relationship building, which is currently not provided for within the NDIS framework.

As a result of these four shortcomings, the approach taken to legal capacity within the NDIS process breaches Article 12. This is indicative of deeper tensions in the NDIS between divergent conceptualizations of personal autonomy.

4.3. Competing Models of Autonomy

The NDIS was developed based on both principles and pragmatism, with the imperative for change being framed as both (a) realizing human rights—ensuring the protection, promotion

⁷ The provision does not specify *legal* capacity, but the provision is about making decisions with legal implications.

and fulfilment of the human rights of persons with disabilities; and (b) promoting economic change—responding to demographic changes and productivity concerns by extending neoliberal marketization policies to the provision of disability supports and adopting an insurance based approach to the funding of supports (Commonwealth of Australia 2011). Both these reform agendas dovetailed in their promotion of individual choice and control. However, the way the two different agendas conceptualize this choice and control, and the models of personal autonomy they reflect, are different.

As discussed above in Section 2, the CRPD adopts a relational understanding of autonomy, where the need for supports is embraced. As explained by Davy, the ‘human rights subject is an embedded self: she is an individual with agency, but an individual who can only exercise this agency with the support of the people and institutions around her. Through the realization of rights such as the right to live independently and be included in the community she develops her capabilities and her capacity for autonomy to the fullest.’ (2017, p. 216). On the other hand, under the individual, libertarian model of autonomy, which underpinned the marketization and insurance reform agendas, the ‘subject is an entrepreneur of the self: she formulates personal goals and aspirations, and, with her new purchasing power, negotiates the true arena of individual freedom, choice and control—the market—to pursue her interests’ (Davy 2017, p. 215).

The design of the NDIS process is primarily based on this libertarian model of personhood, which does not fully recognize the relational environment in which persons with disabilities are embedded and the supports they may require to exercise their choice and control. This leads to an uneasy situation where a scheme that seeks to meet Australia’s CRPD obligations is not aligned with the core principles of the CRPD and the conception of personhood it champions. If the NDIS is to meet its stated human rights objectives, as well as its economic ones, it must shift towards embracing a more relational, dynamic understanding of personal autonomy, one that recognizes the centrality of decision-making supports to exercising legal capacity and securing personhood.

5. Reform Recommendations

To ensure the NDIS complies with Article 12 of the CRPD, a number of amendments are required to the NDIS Act and its accompanying rules. This section aims to provide a high-level overview of the changes needed and flag issues for further consideration.

First, the qualified recognition of the legal capacity of persons with disabilities in the general principles section of section 4 of the NDIS Act should be immediately replaced with a statement recognizing that all persons with disabilities enjoy legal capacity on an equal basis with others, without discrimination. An amended provision could take the following form:

‘People with disability have the same right as other members of Australian society to be able to enjoy legal capacity on equal basis with others, including the right to exercise choice and control.’

This could also be supplemented by including the first principle of the National Supported Decision-Making Principles, that ‘all adults have an equal right to make decisions that affect their lives and to have those decisions respected.’

The recognition of a right to legal capacity on an equal basis with others, should be carried throughout the entire Act. All presumptive, qualified or conditional language, that restricts the recognition and enjoyment of legal capacity on the basis of perceived or actual decision-making abilities of a participant, should be removed.

Simultaneously, the federal government should immediately begin developing a decision-making supports regime or framework in respect of the NDIS process, that is grounded in a relational theory of autonomy. This will involve considering a number of interrelated factors that are explored in further detail below. In conjunction with introducing a support regime into the NDIS Act, the provisions and rules that create and apply to the nominee scheme should be repealed, with appropriate transitional measures for participants who have a nominee, particularly those whose nominee was appointed by

the CEO. The NDIS Act should also be amended to provide that in situations where a participant has a state or territory-appointed guardian, administrator/financial manager, or other type of substituted decision-maker, that appointed decision-maker is not permitted to act on the participant's behalf in the NDIS process.

In the interim period, whilst the support regime is being developed, careful consideration must be given to how the nominee scheme is conducted, in particular whether the CEO should refrain from appointing any new nominees and whether the most egregious aspects of the nominee scheme should be amended, for example, that a participant cannot terminate the nominee arrangement if they wish.

Resolving these issues and designing the support regime for the NDIS process (including the drafting of all amendments and new rules to introduce the regime) should be undertaken in close consultation with disability representative organizations, with persons with disabilities from diverse backgrounds actively involved in every stage.

There should also be close consideration of empirical evidence. The CRPD has spurred a growth in research efforts to determine the efficacy of programs and mechanisms for delivering or providing access to supports and to identify best practices. For example, a project in the US is seeking to build a rigorous evidence-base around how types and methods of decision-making supports impacts self-determination, life satisfaction and community inclusion and participation (Burton Blatt Institute 2019; Arstein-Kerslake et al. 2017). In the Australian context, there are a number of state and territory-based pilot projects that have explored or are currently exploring how best to support people with decision-making, including in the NDIS process (Bigby et al. 2017; Arstein-Kerslake et al. 2017). The findings from these programs, and academic evaluations of them, constitute valuable sources of information that should be closely considered and used to inform the design of the NDIS decision-making support regime. However, the necessary legal reform should not be delayed based on arguments that a stronger empirical evidence-base is required before any action is taken. As argued by Gooding (2015), a lack of empirical evaluation of guardianship has not prevented its continuation and there are 'no plausible reasons as to why domestic law, policy and practice could not be generally reshaped according to the CRPD Committee's elucidation of the right to legal capacity in international human rights law' (p. 70). Once a decision-making supports regime is introduced, quantitative and qualitative data collection and ongoing evaluation can and should be undertaken, in collaboration with disability representative organizations, to continually refine and improve the use of decision-making supports in the NDIS process.

5.1. Nature of Decision-Making Supports and Governance

As discussed in Section 2.2, supports for the exercise of legal capacity can take many forms. On the more formal side are legally recognized supported decision-making arrangements. The ALRC made some recommendations in respect of how such a formal decision-making regime could operate in the context of the NDIS. It recommended that a 'participant or prospective participant should be able to appoint a supporter or supporters at any time during their engagement with the NDIS' (Australian Law Reform Commission 2014, para. 5.49). Only the participant would have authority to appoint a supporter and suspend, amend or revoke the appointment. The participant would also determine the specific functions of a supporter and retain ultimate decision-making authority (Australian Law Reform Commission 2014, paras. 5.46, 5.50, 5.51). The ALRC also recommended that the NDIS Act should include clear provisions regarding the functions and duties of supporters, consistent with the National Decision-Making Principles (Australian Law Reform Commission 2014, paras. 5.59–5.60). These recommendations are consistent with the principles put forth by the CRPD Committee and commentators to guide the development of a CRPD-compliant support paradigm (discussed in Section 2.2). They should be used as the starting point for the formulation of the more detailed provisions and rules needed to establish a formal decision-making support regime in respect of the NDIS process.

The ALRC also recommended that their proposed representative model be incorporated in the NDIS Act. The government should approach this recommendation with caution. The representative model represents a limited departure from the CRPD approach, as it maintains elements of substitute decision-making (Alston 2017, p. 24). The fact that the model allows a representative to be appointed by a third party, does not in and of itself violate the prohibition of substituted decision-making, if it is used in situations of last resort where the individual's will and preferences are not known and decision needs to be made urgently (Committee on the Rights of Persons with Disabilities 2014, para. 21; Arstein-Kerslake and Flynn 2016, p. 477). However, in these instances, the General Comment makes it clear that any decision made by the third party decision-maker must be based on their best interpretation of the person's will and preferences at the relevant time. It is here where the ALRC's recommendations depart from General Comment No. 1, as it provides that: (a) 'if it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's human rights and act in the way least restrictive of those rights.' (Australian Law Reform Commission 2014, p. 12); and (b) 'a representative may override the person's will and preferences only where necessary to prevent harm.' (Australian Law Reform Commission 2014, p. 13).

The best interpretation approach put forth by the CRPD Committee in its General Comment No. 1 provides that where it is not practicable to determine a person's will and preferences, after significant efforts have been made including through the provision of support, the best interpretation of will and preferences should form the basis of decisions that need to be made. As explained by the Special Rapporteur on the rights of persons with disabilities, the 'standard implies ascertaining what the person would have wanted instead of deciding on the basis of her/his best interest. The process should include consideration of the previously manifested preferences, values, attitudes, narratives and actions, inclusive of verbal or non-verbal communication, of the person concerned' (Special rapporteur on the rights of persons with disabilities 2017, para. 31). While reaching this best interpretation of will and preferences will no doubt be a difficult task in some cases, 'it is the use of this process, with the end goal of respecting will and preferences' (Arstein-Kerslake and Flynn 2016, p. 478) that distinguishes it from substituted decision-making. It shifts the framing and encourages innovation in methods to identify will and preferences—and where not practicable, to reach the best interpretation of will and preference—including reliance on a range of communication modalities, the use of new technology⁸ and building a holistic view of the individual.

While the ALRC's recommendation that a representative must act to promote and uphold the person's human rights is a good one and in line with Article 12(4)'s reference to 'will, preferences and rights', this requirement must be secondary to their requirement to act in accordance with the best interpretation of the person's will and preferences.

The fact that the ALRC's recommendations did not fully embrace the best interpretation approach as the central standard to be applied by a representative means that it allows scope for an objective best interest test to be used, contrary to Article 12. This is particularly evident in recommendation (b) extracted above, which provides a lower standard for denying the legal capacity of a person with disability in situations of harm or a risk of harm than is applicable to people without disability.⁹ This is contrary to the first of the National Supported Decision-Making Principles, that all adults have an *equal* right to make decisions that affect their lives. Accordingly, while there is a place for the representative model proposed by the ALRC in the NDIS, the model should be amended to ensure that the best interpretation of will and preference approach is fully adopted and substituted decision-making is not permissible in any circumstances.

⁸ See for example the work of Naci and Owen (2013) around the use of magnetic resonance imaging to establish a form of brain communication with people in a coma.

⁹ For a further discussion on the issue of decisions based on will and preferences potentially resulting in harm, see Arstein-Kerslake and Flynn 2016, pp. 482–83.

In addition to formal supported decision-making arrangements, the NDIS Act must acknowledge and support the diversity of decision-making supports. It should solidify and provide greater scope for the use of a broad range of informal supports for the exercise of legal capacity, including support from families, carers, advocates and peer support groups. As stated by the ALRC, 'providing mechanisms for the appointment of formal supporters and representatives under the NDIS Act should not diminish the involvement of and respect for informal support in decision-making' ([Australian Law Reform Commission 2014](#), para. 5.47).

Additional provisions and rules in respect of informal decision-making supports in the NDIS process should not be too prescriptive, and participants should not face pressure to formalize existing, effective informal decision-making support arrangements. On the other hand, the provisions must balance concerns of over-regulation with a recognition that some informal arrangements may in fact restrict participants' exercise of legal capacity, as their decisions are informally made on a substituted basis. To strike the right balance, the provisions should focus on providing a broad framework that encourages and facilitates participants' access to and use of a range of supports, drawing on the existing general principles of the NDIS Act, which recognizes the importance of support and the role of families. The ability of participants to be joined by trusted persons during their NDIA planning meetings reflects an existing recognition of the role of informal supports. The use of informal supporters and varying support mechanisms and programs during other phases of the NDIS process should likewise be recognized and facilitated. This could include, for example, financial literacy training and administrative support to help NDIS participants manage their NDIS funds and access and manage NDIS supports.

5.2. Funding of Decision-Making Supports

A second matter that needs careful consideration in designing a support regime for the NDIS process is how decision-making supports could be funded. One obvious option is that decision-making supports could be classified as reasonable and necessary NDIS supports and funded for individuals under their NDIS package.

This, however, gives rise to some issues for potential NDIS participants that need to be worked through. If decision-making supports were to be funded via a NDIS plan, this would mean that a new applicant would not receive any funding for the supports that may need in exercising their legal capacity in the initial steps of NDIS process, namely proving eligibility and developing their first NDIS plan. This represents a time when participants may potentially need a greater level of decision-making support than they may otherwise need, as they navigate the NDIS for the first time and make crucial decisions that will shape their NDIS package going forward. This gap in initial funding for supports therefore would have to be addressed. This could be via separate funding for supports that may be required during the initial NDIS process. Alternatively, the State could play a more direct role in providing or facilitating the initial supports required (this is considered further in the next section below).

Beyond decision-making supports for the NDIS process, there is also potential for the NDIS to be used more broadly to fund supports for the exercise of legal capacity *in all* aspects of life. This could be done by recognizing decision-making supports as part of a participant's reasonable and necessary disability-related needs that are funded under a NDIS plan. This needs further consideration, as part of broader work to develop a 'comprehensive system to coordinate the effective access to supported decision-making of persons with disabilities' ([Special rapporteur on the rights of persons with disabilities 2017](#), para. 66). One matter that cannot be ignored is that only around 10% of persons with disabilities in Australia are eligible for an individualised support package under the NDIS ([Disabled People's Organisations Australia 2017](#), p. 8). If funding for decision-making supports is only to be made available to NDIS participants, then this ignores the majority of persons with disabilities that may require support to exercise legal capacity. Under Article 12, Australia is obliged to provide to *all* persons with disabilities.

5.3. Role of the State in Providing Supports

Finally, the role of the State in directly providing decision-making supports for the NDIS supports needs to be carefully considered. Article 12 does not mandate that States must provide supports to persons with disabilities, rather that they must ensure *access* to supports. The CRPD Committee and UN Special Rapporteur on the rights of persons with disabilities have further clarified that the obligation to ensure access includes the obligation to facilitate the creation of support.

The NDIS Act envisages a role for the NDIA in respect of directly providing participants and prospective participants with support 'in relation to doing things or meeting obligations under, or for the purposes of, this Act' and in 'their dealings and communications with the Agency' (ss. 6, 17A(2)). However, the extent and precise nature of the NDIA's support role is far from clear. Most notably, the duties of the NDIA agents in providing support and assistance are not specified. These duties must be developed along with clear guidance regarding how NDIA agents are to manage: (a) the uneven power dynamics between themselves and the participant and; (b) the conflict of interest between their dual gate-keeping role of providing support to persons with disabilities and working as agents of the NDIA, a body ultimately answerable to the federal government. While skilled and sensitive NDIA planners and coordinators are no doubt essential in the NDIS process, there is a need for their support role to be clearly delineated, and wide latitude given to individuals to use independent supporters and support mechanisms.

Separate to the NDIA, the National Disability Advocacy Program (NDAP), managed by the Department of Social Services, is mandated to assist persons with disabilities in the NDIS process and is running a Decision Support Pilot. NDAP is available to 'assist people to participate in decision making and increase their capacity to understand the service delivery options available to enable them to meet their goals' (Commonwealth of Australia 2018).

While this purview of the NDIA is welcome, as is the recognition of advocacy as an important type of support, advocacy is but one type of support persons with disabilities may need in decision-making. States are required to provide access to 'the fullest possible range of support to the diverse population of persons with disabilities' (Special rapporteur on the rights of persons with disabilities 2017, para. 29). Therefore, further consideration must be given to how the federal government can best provide and/or facilitate the creation of this diverse range of community-based supports. The separate Information, Linkages and Capacity Building (ILC) stream of the NDIS seems the appropriate space for efforts to facilitate the creation of supports, but to date there has been little consideration of using the ILC in this way.

6. Conclusions

The NDIS is the centerpiece of Australia's efforts to implement the CRPD. The national framework it has established to fund supports that may be needed by persons with disabilities to live independently and be included in the community is a significant step forward in implementing some of the core aspects of the CRPD. However, it is disappointing that decision-making supports were not included as essential scaffolding for this framework. This missed opportunity suggests that the notion of personhood at the heart of the CRPD has not been fully understood and internalized. For this to occur, the foundations of the NDIS need to be untethered from a liberal model of autonomy and instead move towards embracing a relational model of autonomy that recognizes and provides for a decision-making support regime within the NDIS process. Such a decision-making support paradigm is crucial for persons with disabilities in Australia to be given real choice and control and a real opportunity to increase their social and economic participation. This, in turn, is crucial for the NDIS to live up to its own objectives of supporting independence and enabling choice and control, as well as meeting the requirements of the CRPD.

Ideally, reform to accessing decision-making supports for the NDIS process would be situated within wider, comprehensive legal capacity law reform across jurisdictions that dismantled all forms of substituted decision-making (including guardianship regimes across jurisdictions) and introduced a

national system to coordinate the effective access to support for all exercises of legal capacity. The lack of measures taken since the ALRC's 2014 report does not bode well in this respect. However, as the ALRC noted, the NDIS represents the primary area of Commonwealth law in disability policy and therefore the primary area in which reform to legal capacity can have widespread effect ([Australian Law Reform Commission 2014](#), para. 5.8). In this way, it can play a leading role in demonstrating how decision-making supports work, initiating cultural change and creating an expectation of uniformed supported decision-making laws across jurisdictions. The efforts of disability organizations and rights campaigners may therefore be best dedicated to pushing for amendments to the approach taken to legal capacity within the NDIS process, utilizing the NDIS Act's own stated objectives of maximizing choice and control for all persons with disabilities and implementing the CRPD. This could then be used as a catalyst for wider-scale reform of legal capacity laws throughout Australia.

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