# Response to the National Disability Insurance Scheme consultation paper: ‘*Supporting you to make your own decisions*’

*Submission date: 10 September 2021*

To whom it may concern,

thank you for the opportunity to provide this submission to the National Disability Insurance Scheme (NDIS) consultation “*Supporting you to make your own decisions*.”

My immediate comments below contextualise my fuller response to the “*Supporting you to make your own decisions”* consultation, and which follow on past this sub-section (I’d apologise for the length of this document, I found out about the consultation late and so this is all last-minute drafting):

* I write to you as a private citizen and in context to a family member, my sister, who has a lifelong profound intellectual disability. She is in her fifth decade of life and currently resides in an organisation that provides year-long 24/7 care. I am subject to the provisions of the *National Disability Insurance Scheme Act (2013)* as my sister’s plan nominee. I also hold a financial order imposed by a state-based tribunal and associated authorities flowing from that order (Medicare, Centrelink, Taxation Office, financial institutions, *etc*). I operate as a decision-supporter (additional to a community of persons from the organisation that cares for her on a day-to-day basis), as well as substitute decision-maker across major life decisions and as person responsible in managing her health. The “*Supporting you to make your own decisions”* consultation is directly relevant to my sister’s quality of life and my role as a decision-supporter, as her plan nominee and (sad as I at times feel about it) substitute decision-maker.
* In this submission and as related directly to my experience, I restrict my comments only to ‘persons with a Severe or Profound Intellectual Disability (SPID)’ (although I recognise that the difference between severe and profound intellectual disability can be substantive and complicated). I also note that there are people with other types of significant cognitive challenges and who may broadly fall into the same remit for action as persons with SPID, of which my comments may or may not be relevant too.
* It is excellent to see this consultation “*Supporting you to make your own decisions*”, as the topic is central to the success of the NDIS and very much needed. I’d also like to say that the NDIS has substantially improved my sister’s quality of life and for that I am more than grateful. Sadly though, my experience of the NDIS has been that it is administratively complicated, opaque and exhausting to deal with. My commentary in regard this consultation is tinged with this bifurcated complexity; the joy in seeing that in recent times the social contract has been extended more fully to my sister against the substantive increase in administrative and legal complications that have come with this extension.
* I intend to use the word ‘carer’ for a person with SPID to *include* those formal (*eg*., staff in an institution) and informal (*eg*, family and friends) persons who have a long-term shared history together or who are in direct day-to-day managerial contact with a person with SPID. I do this deliberately, as older persons with SPID are likly to be in an organisational environment where day-to-day care and support for decision-making comes from employees whilst oversight, life-level decisions and connections external to the organisation stem from family, friends or in some cases formal representatives (*eg*., a legal guardian). This mix (of formal/informal) is critical to model into a system for decision-support for persons with SPID and I want the word *carer* to do this kind of work within my response here.
* Throughout my response, I will refer to the consultation papers (NDIS (2021a) and NDIS (2021b)) as the (Decision Support) ‘DS consultation’.

# The paradox at the heart of the NDIS: ‘It is all about supported decision making until it’s not, then its substitute decision making all the way’

The DS consultation firmly announces its aim as being:

"*...particularly important for participants with complex needs including those with significant cognitive impairment*" (NDIS 2021a: 3).

This is no doubt a soon to emerge truth as the DS consultation goes from an idea to policy implementation, but I am going to make the argument that the DS consultation fails to adequately deal with the communicative and epistemic dilemma posed by persons with SPID (*ie*., how can we *reasonably* know what they know) and the impact this has on the way that decision-support is shaped in the DS consultation. In essence, the DS consultation does not go as *far as the NDIA might reasonably be able to go*, for replacing substitute decision making with supported decision making. This problem has been with the NDIS since its inception. The DS consultation is just a further example of the difficulties the NDIS imposes on itself (of which the NDIA and its over-prescription of the plan nominee role is but a part) and on carers who have to deal with markedly different ways in which support for people with SPID can unfold as compared to those with moderate or milder forms of cognitive disability. In this, my primary argument is that the DS consultation needs to be re-written to adequately contextualise the challenge that persons with SPID present to decision-support for people with disabilities (and then re-released for further public comment). To do this, I’d like to take an example (of many) from the DS consultation to show how the consultation fails persons with SPID.

Throughout the entire DS consultation, excepting perhaps the decision-support techniques mentioned in the companion paper (*eg*., microboards) (NDIS 2021b), the presented model of disability and decision-support encapsulates a one-size fits all approach that, when viewed closely, is weighted towards persons with moderate through to having no cognitive disability. This hides the challenge that persons with SPID create for good decision-support policy-making. For example, Figure 3 (“Life stage, decision examples; and strategies to build capacity”) of the main consultation paper (NDIS 2021a: 13) is an exemplar of this problem:

* When I place my sister into the combined Figure 3, and no matter where she could broadly be dropped into it at, I get a *simultaneous* mix of *some* items in the column ‘Children<12’ and some items in the column ‘Aging (>55)’ – this is unsurprising, as if you have severe neurological damage there is not much further you can develop from or degrade to no matter what age or stage of life you are at. Any heuristic (which is what Figure 3 could be said to be operating as) that confuses its components when layered next to the context it is supposed to clarify, is not a useful heuristic. All in all, I can see how Figure 3 could be useful to someone with a moderate to mild intellectual disability or some other cognitive or decision-making issue, but I do not believe it is useful for persons with SPID.
* The above generalisation in Figure 3 is crystalised in particular in Figure 5 (“Suggested options to support different levels of decision making capacity”), of the main consultation paper (NDIS 2021a: 20). It outlines a ‘young adult exploring housing options.’ Matching my sister to Figure 5 leads to her being placed entirely in the column set (all three cells) marked in green and summed as “*Participant needs substitute decision maker for all decisions*” (NDIS 2021a: 20). Nowhere in the DS consultation is this summed statement unpacked in any understandable way that enlightens the reader as to what decision support for persons with SPID actually might look like (outside of global statements such as “*We* [the NDIA] *will keep encouraging substitute decision makers to involve you in decisions about you and help you to practice your decision making*” (NDIS 2021a: 15) or, at best, inference that things may be better with the choice of appropriate techniques (in the companion paper (NDIS 2021b)) for altering the way decisions are made.

The problem outline above does not emerge in a vacuum, it is foundational to the NDIS and can be seen in the ideal (*ie*., vision) for decision-support that the NDIS inherits from the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

The NDIS is a laudable policy for putting into action Australia’s obligations under UNCRPD. On page 6 of the DS consultation, it is explicitly stated that:

“*Article 12 [of the UNCRPD] recognises that people with disability have the same legal capacity as others in all aspects of life. Article 4 of the CRPD requires nations to replace substitute decision making with supported decision making in a way that respects a person’s will and preference... . Along with other laws, the NDIS Act helps put Australia’s obligations under the CRPD into practice*.” (NDIS 2021a: 6).

On the surface, this statement is paradoxical as Australia uses substitute decision making systems across all jurisdictions and the commitment to keeping the current systems appears unperturbed by the obligations under UNCRPD. Specifically, within the NDIS Act, the plan nominee role operates as a substitute decision making system (and not disregarding the aim to reduce the number of plan nominees, no change is suggested within the DS consultation as to the structure of the plan nominee role). The admonishment within the DS consultation to replace substitute with supported decision-making whilst also continuing to support substitute decision-making in the plan nominee system embeds a (presently) unreachable ideal into the public consciousness and in terms of NDIS policy-making. It seems to underlie a confused model of disability and decision-support within the DS consultation that effectively puts persons with SPID into the ‘too hard basket’ (for the time being), as the presented model does not match their lived reality.

This needn’t be the case though, if the NDIA and associated power centers (*eg*., the Minister for the National Disability Insurance Scheme and Minister for Social Services) could reframe the vision for going from substitute to supported decision-making that more likly matches the reality of what is happening now. For instance, the NDIA could clearly state that:

* a pre-existing legislative and legal system in Australia that legitimates substitute decision-making is here for the foreseeable future;
* it will take quite some time to change how this all operates (possibly a decade or more);
* that the NDIS is an experiment and an opportunity to shift part of this system to be more sensitive to supported decision-making but for some people with disabilities a form of substitute decision-making will remain in place; and,
* that along the way there will be struggles and ‘roads best not taken’ (*eg*., failures, like over-prescribing plan nominees) and we all need to be as kind to each other as possible as we surface what does not work in order to more adequately craft what does work.

Nothing in these dot-points above are new and they emerge from existing NDIS and related materials, but a reframing may offer an opportunity to make it clearer to those of us who do decision support for persons with SPID why the substitute decision system seems fixed in place whilst other initiatives occur to empower people with disabilities (so reframing makes the paradox more understandable).

The basis for reframing is easy, as it is already supplied elsewhere in UNCRPD - within Australia’s entry under the ‘declarations and reservations’ to the UNCRPD. This entry modifies the meaning of Article 4 and 12 (as this is a normal process where nation-states can clarify the scope of a UN treaty), to wit:

“*Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards*” (United Nations Treaty Collection 2006).

This vision is the more realistic vision because it makes clear that substitute decision-making, especially for persons with SPID, is here for the foreseeable future and it is a hard problem (to alter). Moreover, it makes *explicit* something the DS consultation makes *implicit*; that is, persons with SPID require (forms of) substitute decision-making whilst everyone else in the broader population of the disabled will be engaged with an effort at clarifying supported decision-making (so clearly seen in Figure 5). The paradoxical nature then of the DS consultation seeming to say (in my words) that it is ‘*all* about supported decision making until it’s not, then its substitute decision making all the way’, can be reframed to deal with the cognitive (and legal) complexity of persons with SPID. This does though lead to an uncomfortable outcome – persons with SPID need to be in a separate category within the population of people with disabilities and that needs to be formalised within the DS consultation then further linked to a mechanism for decision-support change for persons with SPID (as the eventual aim, I would gather, is to make substitute decision-making a rare requirement, which is where the DS consultation may one day want to arrive at once actioned).

Therefore, in terms of requirements that may stem from the discussion above and which could be added to the outcomes from the DS consultation (to date), I’d suggest considering:

1. Add Australia’s entry under the UNCRPD ‘declarations and reservations’ to the vision for how we get from a historical system with a strong emphasis on substitute decision-making to one where the legislative, legal and practical ramifications of supported decision making are the dominant way in which we deal with all people with cognitive disabilities. The production of a clear and prominent statement that the NDIS aims to meet the UNCRPD requirements that ‘substitute decision making is replaced with supported decision making’, but the NDIS realistically understands that this may take policy experimentation and public education over time and so has adopted a model of *incremental change* to decision-support systems and legal structures in order to meet that aim (this seems to actually be inferred in the DS consultation, but needs to be explicit).
2. Eventually, publicly aim (if possible within a UN treaty) to re-write Australia’s entry for UNCRPD ‘declarations and reservations’ to state that substitute decision-making is reserved for rare cases and for short time frames and one day, can be removed all-together. A worthy goal if there ever was one.

# The critical need to theorise the phenomenology of people with SPID, as this group within the NDIS present the most challenges to decision-support

Persons with SPID present a challenge to decision support processes that are shaped to work with persons who have moderate to mild or no cognitive disability. As a general statement, persons with SPID can have irreversible neurological damage, be incommunicate, with an IQ of <25 (if even measurable) and with substantive impairment in some, and possibly all of, communication ability; self-care; social/interpersonal capacity; use of community resources; self-direction; functional abilities; and, health and safety skills. How this works out at the individual level of a person with SPID and the challenges this presents to decision-support can be seen in the following statement drawn from an article on how persons with profound intellectual disability engage others in interaction:

“*If the [SPID] person with impairments has some language abilities (as not all do), their command of vocabulary and prosody will be limited, as will be their command of morpho-syntactic form (interrogatives, declaratives and so on (and here it is relevant that ... suggests that most ‘pick-ups’ are in question format; that is, that neuro-typical speakers often start up conversations with an interrogative). People with SPID may not have the capacity to find words, and control grammatical form and intonation, to specify that a response is wanted from the next speaker (let alone what kind of response). If they can vocalise at all, then the actual delivery of what they utter will often be unclear... The situation with epistemic asymmetry ... is still more cloudy. Epistemic status is the authority someone has to know about, and speak to, a given situation... Where there is an epistemic imbalance between two people, the one with less ‘ownership’ of the case will require response from the one with more (such that, for example, the apparent declarative ‘You’re late’ mobilises a response from the recipient, who can, and now ought, give the reasons). Given the intellectual limitations of people with SPID, the epistemic status of what they say (if it is intelligible) will be a very difficult matter to gauge, and may not reliably prompt a response in the same way as would an utterance by a neuro-typical person. In sum: lexicomorphosyntax, prosody and epistemic status, are likely to be out of bounds for the person with SPID; it is gaze and posture ... which are likely to be the initiators most under the control of the person with SPID.”* (Antaki *et al*., 2017: 583).

Without a basic understanding of the differences in cognition presented by persons with SPID as compared to those with greater cognitive capacity, it will be difficult to undertake the process of moving away from substitute decision-making as supported by techniques more relevant to the challenges of difficulties in ‘lexicomorphosyntax, prosody and epistemic status’, let alone other socio-cultural and physical issues presented by persons with SPID.

Therefore, in terms of requirements that may stem from the discussion above and which could be added to the outcomes from the DS consultation (to date), it looks a little like this:

1. Recognise that persons with SPID need to be put into a sub-category of all persons with disability in order to deal with the significant challenges SPID creates for decision-support systems (both cognitively and legally). It will be difficult to do but the reward warrants the challenge, as reducing the need for substitute decision making in the population that is most likly to require it (persons with SPID), will have positive follow on affects for those who do not need or need less substitute decision-making (being the rest of the population of disabled persons).
2. In order to advance the above goal (in point 3), the NDIA should investigate (and/or support research for) the literature that broadly falls into the topic of the phenomenology of persons with SPID (like the above article by Antaki 2017). The aim being to create a generalised model (theory) of a person with SPID and use that to sensitise carers on one hand and to search for and implement decision-support techniques alongside changing legislative and legal systems on the other hand. The final outcome is to present a phenomenological understanding of (i) the lived reality of people with SPID; (ii) a description of how this lived reality affects the context in which people with SPID may require decision support; (iii) the central role of decision supporters in imaginatively displacing themselves into a tentative ‘being’ with an individual person with SPID; (iv) towards intuiting and evoking a decision from the decision supporter; and, (v) that then can be put through a technique of decision support towards producing actionable decisions.
3. The following idea draws from some of the material in the DS consultation but alters it and I also flag that it may be worth making this the object of a legal (legislative) framework. That is, to focus on the community (hopefully, where it exists) of people who surround a person with SPID and formalise it as the locus of decision-making. In the DS consultation, the part of the principles and goal listings that works for people with SPID is “...*the availability and skill of the people who can support you*“, and also “*Build the capacity of decision supporters, agency staff and partners to recognise and enable the will and preference of participants*“ (NDIS 2021a: 25). Broadly speaking, I would concentrate on these to draw the singular focus on decision capacity away from the person with SPID in order to add the decision-supporters, so all are together as one singular decision-making unit. This would highlight that the decision-supporters need in turn to be supported to interpret how a person with SPID makes meaning in the world. It would require the DS consultation ideal of “*exercise real choice and control*” and “*Support the development of your capability in making decisions”* (NDIS 2021a: 9)be removed from the key goals and principles for people with SPID and to be replaced by something like: ‘To be supported in having my *potential* decisions *interpreted* into action by my decision-supporters’. The qualifications of ‘potential’ and ‘interpreted’ are deliberate and necessary. It eases back the certainty of knowing that we can increase “*real choice and control*” and that we can “*development your capability in making decisions*” in the face of the reality of the likly capacity of a person with SPID. That the decision supporter must grapple with the ‘unknowability’ of someone who is incommunicate, who presents a substantive epistemic dilemma (in many cases, we can’t know they know, *eg*., something important, like ‘what is this medication’) and for whom any semblance of recognisable socio-cultural expression is intermittently conflicted and confusing, all brings a differing focus to how a decision gets made. It co-ordinates the experiential challenge of the SPID and the decision supporter *together*, into a relational dynamic that itself becomes the center of interpretation for decision making. In other words, decrease the dissonance produced by the current DS consultation goals and principles and increase the opportunity for something we might broadly recognise as success in regards decision-support for people with SPID, essentially by altering the way we think about how decisions are made and by whom.

# The plan nominee role needs reform: Its existence runs counter to the aim of replacing substitute with supported decision-making

I’d like to recognise, and it is positive to see, that the NDIA is looking to clarify the plan nominee role:

“*When a nominee appointment is required, we have the opportunity to offer better support for nominees. This will help them to recognise and enable your will and preference. It will also help them to provide opportunities to build your capacity for decision making*” (NDIS 2021a: 17).

My experience of the role (and the dysfunctions that came with it) reinforces the above approach from the NDIA in regard further support to plan nominees, but I’d like to go a step further and suggest that the plan nominee role be altered so that it becomes a role held by a professional (similar to the support coordinator role) and that the responsibilities of a plan nominee be transferred to community of decision supporters that surrounds a person with SPID.

I am a plan nominee for my sister and have found it, amongst the set of authorities I hold, to be the most unclear and problematic in use. The role clearly has a legislative basis with legal and administrative consequences and appears to be a hybrid between a nominee role, like that seen with Centrelink or Medicare, and a financial, guardianship and/or person responsible type substitute decision power. The DS consultation explicitly states that the plan nominee role has this flavour, when it states: “*Reduction in substitute decision making – e.g.: nominee appointments*” (NDIS 2021a: 26). It is this hybrid like appearance alongside the particularities of NDIS plan management that contributes I think, to confusion. Adding to this, is that there appears to have been substantive implementation problems for the NDIA regard the role.

Just to give one example that shows the extent to which the plan nominee role has had substantive issues (at least in my experience) is that it took me from late 2016 to early 2018 (over two plan cycles) to obtain the plan nominee role. Instructions given by the NDIA and administrative functionality in regards the applications were confused and dysfunctional (over three application attempts). Further, in my sisters current NDIS plan cycle, her provider and I were ‘disappeared’ from the cycle (no matter seeking ongoing clarification if there was a problem) and the NDIS made a substantive reduction in my sister’s plan without consulting any of us. The crux of the matter here is (less the particulars of the issues above but more) that for a substantive period of time - (i) before I was granted a plan nominee role, and (ii) in this current year NDIS plan cycle - the NDIS has made decisions in regards my sisters plan when either I wasn’t her plan nominee but I was making all the same kind of decisions as to if I was her plan nominee; and, the NDIA can clearly make substantive decisions over a plan without the participant, plan nominee, support coordinator or provider being involved. What this all amounts to, is a whole pile of confusion.

I don’t wish to further unpack problems I have experienced with the role, but I will make some general statements by comparing the NDIS plan nominee role to the state-based system in the table below. My experience in that system, in which I hold a financial order (although challenging in a variety of ways), were functional.

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| --- | --- | --- |
| **Context** | **State-based tribunal** | **NDIA** |
| Transparency | Largely transparent as to what would happen as the process and outcome unfolded. | Lacked any meaningful transparency as to what would happen as the process and outcome unfolded. |
| Decision context | The decision by the tribunal regards an order are made in a formal meeting setting with all those involved, and the resultant outcome is explained in a report available to the participants. | No explanation as to how the decision to grant the nominee role was made (just a single letter confirming the plan nominee role and responsibilities under it). |
| Weighting of decision | Conservative decision over granting an order; which is to say that the tribunal provides the least restrictive outcome onto the person (who may be coming under an order). | Early public confusion over how the nominee role was being managed (conflation with guardianship) and who was being enrolled and now, as this DS consultation states, the NDIS has over-prescribed the role. |
| Division of power | Effective division of power; where the granting (of an order) body (*ie*., the tribunal or court) is not the managing body (*ie*., the government department tasked with oversighting the person who is granted the order); which means that problems with the managing body can be taken to the granting body for resolution. | No division of power; the NDIS both grants and manages the role; which means that problems with the managing body are to be resolved by the managing body (unless substantive escalation is required for judicial review). |
| Experience in managing | Significant historical and organisational experience in dealing with the challenges of decision making. | No organisational experience apparent (whether from the NDIA or other Federal bodies) in supporting plan nominees in their role or reviewing issues with the role are evident. |

My response to some of the issues outlined in the table above is to try and break the plan nominee role away from a single person (like myself) and, in part, separate the authority component (who has legal capacity to agree to decisions) away from how decisions are made (*ie*., on the ground for a person with SPID), much of which are made in the context of an *entire* life rather than a specific ‘NDIS life’ – what this may do is to clarify the plan nominee role alongside actually reducing substitute decision-making.

Regards the NIDA, and although the NDIA states that the plan nominee role is specific to the NDIS, in practical terms the decision making that stems from it can encompass an entire life. For somebody like my sister, her NDIS plan supports where she lives, who looks after her on a day-to-day basis and the bulk of the activities she does in her life. Her other supports which are independent of the NDIS are largely structured secondarily (and in support of) the outcomes that stem from her NDIS plan but combined make for a life greater than that defined by the NDIS. My being a close family member and the person who holds a variety of formal powers over my sister, and considering the extent of her cognitive incapacity, makes me her substitute decision-maker by default. It is therefore unsurprising that the NDIA would wish to authenticate a single substitute decision-maker to its system when the NDIS participant is unable to hold legal capacity. What I am saying here though, is that the NDIA sees the plan nominee role as being defined by the NDIS as a whole (as evident in the statement; “*An NDIS nominee only makes decisions that are related to the NDIS*” (NDIS 2021a: 15) whilst I see the plan nominee role as conjuncted with all the various roles that I have to hold over my sister of which the NDIS is *but a part*. Further, to me, the plan nominee role operates as a kind of ‘guardianship light’ yet at the same time that isn’t how the NDIA appears to treat it in practice, where it appears to be some kind of authentication process with attendant responsibilities placed by the NDIA on the nominee (and not vice-versa where the NDIA has responsibilities to the nominee).

So, I’d like to work outwards from the following comment in the DS consultation and also in light of the confusion that stems from the role and which I have highlighted in the table above:

“*We also have the opportunity to put in place strategies to explore alternatives to nominee appointments. This will promote a shift away from the overuse of substitute decision making under the NDIS.”* (NDIS 2021a: 17).

The DS consultation suggests that those who provide decision-support (particular members of the community that surrounds a person with disability) should be identified as part of a NDIS plan process and that they should be given educational supports. I’d like to reinforce this for a person with SPID, as one of the best opportunities to achieve better (empowered) decisions comes from their being in a highly structured and constantly supported environment with what is likly to be a small number of one on one (individualised) care relationships:

1. Formally identify the core decision supporters for a SPID person, *eg*., family, friends and ground staff in day-to-day contact, and the support co-ordinator (who should be external to any provider of general services to a person with SPID). The person with SPID and these identified decision-supporters become the ‘community’ (I’ll use the word ‘collective’ for this section) (this is important for point (3) below).
2. Focus the already suggested curricula development in the DS consultation for those identified in (1) above to cover: (i) which techniques may best help decision supporters of SPID persons (the absolute core though, is to help decision makers understand how to be present as if they were the SPID person making a decision); (ii) how to come to consensus in group decision making; (iii) how to compromise in decision making; (iv) how to handle conflict in decision making; and, (v) a description of the administrative environment that necessitates decision supporters which includes the responsibilities of decision supporters have to the SPID person and in turn the NDIA to decision supporters.
3. Split the plan nominee role into three legal roles:
   1. Make the collective identified in (1) above, a legal entity of some form (I note the Canadian’s have developed a suite of options that might provide ideas for such an action and that safeguards would also be needed for conflict-of-interest issues). Give that legal identity as full a set of rights as possible (I am drawing from Nussbaum 2009) – in essence, it operates as a relational system for conciliating decision support and where required provides substitute decisions for a person with SPID, as *if the collective were a (neuro-typical) person with legal capacity*. At best, it produces consensus decisions that when required for meeting legal needs of the plan nominee role (*eg*., finalise a NDIS plan or agree to a service agreement) are submitted for approval or ongoing management to the arbiter role outlined in point (ii) to follow. If consensus or compromise can’t be reached, or disagreement occurs with the arbiter, then that requires the mediator role (person or panel) outlined in point (iii) below.
   2. Make a professional role held by a single person (not an employee of the NDIA) who is to be an impartial (lawyer-like) arbiter. This is similar to a support co-ordinator role; and would involve managing the administration (of the legal requirements that lie) between the NDIA and the collective (which includes the person with SPID); all across a reasonable number of NDIS participants (so multiple collectives); and, where the collective needs to show the arbiter that consensus has been reached within the framework established for meeting the responsibilities of the plan nominee role.
   3. Make a mediator (facilitator) role (or panel) for those occasions that (i) a collective for a single person with SPID fails to conciliate or compromise and winds up in disagreement/breakdown; or, (ii) where the collective and the professional plan nominee (in (ii) above) are in conflict. This role should have the ability to (i) try and achieve consensus; or; (ii) make a final decision (open to appeal), no matter what the collective or arbiter wish to do. Here too, lies the state-based tribunal and court systems, who can offer a further layer or response or work-around to conflictual situations.
   4. The above outcome would mean that a single plan nominee (like myself), would no longer exist, as effectively there would be three legal entities (only two of which (point (i) and (ii) above) would need to work together at any given time to drive decisions forward).
4. Conduct a review process of how steps 1-5 work as an ongoing assessment over time, to make sure it all keeps working as expected.

In summary, the ideal would be to take the current situation where a single plan nominee authorises a plan as if they were the (person with SPID) participant and is in effect operating as the substitute decision-maker and to instead:

* embed that process formally into a collective that has an understanding of how a person with SPID may indicate their will and preference with a stronger focus on supported decision-making;
* where the above will and preference cannot be interpreted, for the collective to subsume themselves into the place of the SPID person in such a way as to render a substitute decision as best they can as a collective; and,
* where the collective’s decision goes to an plan nominee for a final decision that meets the legislative requirement for a person with legal capacity to authorise decisions.

I know this is layered and more complicated (and resource intensive), but from my experience it is an effort to get a single person like myself out (somewhat) from under being a ‘first among equals’ decision-maker and who winds up being the defacto substitute decision-maker for a person with SPID. By distributing this power into a collective (community) group (that in many cases will already exist), it should force more considered decision-making and bring a further focus to determining the will (as much as it can be determined) of a person with SPID that matches how their day-to-day governance unfolds, which will be inside an already existing community of decision-makers.

# Issues with duty of care: The NDIA needs to more adequately explain how it will support carers doing decision-support

A final matter I would like to raise is that the NDIS is for people with disabilities, first and foremost, but what appears to have been lost is the way that carers are *supported to support* people with disabilities.

My experience of the NDIA is that there is administrative complexity; issues in the competency of policy implementation; a lack of transparency; and, a failure to conceptualise careers as being vulnerable. These kinds of outcomes are unsurprising, the NDIS is new and has an enormous challenge in revolutionising the lives of people with disabilities. Unfortunately, I am finding it wearing to deal with the extent of issues the arise in the routine operation of the NDIS. It shouldn’t be this hard and I worry about the future. In this sense, it has been a benefit to my sister, but it has been damaging to my caring role.

So, the NDIA has not much built into its systems either nuance nor compassion for what is forcing upon all those who have no choice but to be a part of the NDIS. Throughout the DS consultation, there is more layering of responsibilities onto carers but there appears no real conceptualisation of:

* how administrative changes to (a new system of) decision-support may impact on carers;
* what learning how to do decision-support might mean for a carer and how they can be supported in this educative space;
* the emotional consequences to carers in having to learn how to do decision-support formally; *eg*., what happens when a carer realises that their habitual, ad-hoc, lived history of decision-making has not served the interests of a person with SPID person (possibly trauma, guilt and distress);
* the benefit of positive reinforcement to carers in being better decision-makers for both those they care for and in their own lives; and,
* a sensitivity on the behalf of the NDIA that it is in a power-over position to carers and therefore needs to express its own organisational vulnerabilities in a way that communicates this joint decision-support role as a journey in which we all learn as we go and are sensitive to the challenges that might arise in a way that enriches us all, rather than potentially cripples.

What I would like to see from the NDIS regards supporting carers, is:

* Go slower in policy implementation, build in suitable mechanisms for supported feedback and meaningfully communicate to carers on (curated) issues specific to individual carer needs;
* When the NDIA suggests major policy changes that impact on its carer base, it should explain, as best it can at the time, the possible impacts and what steps the NDIA proposes to take to mitigate those impacts (and can be shaped as sensitivity to the vulnerability of carers in terms carers would understand and not externalised to ‘seek it out yourself’ support services);
* The NDIA must strive for as high a level of transparency in regards its own operations, in practice and in what it does not know or where uncertainties are high;
* Try to target support to carers that is sensitive to where carers may be struggling or in crisis;
* Find ways to show how carers can benefit from changes in a way that leaves carers with some sense of hope that a new future is possible;
* a consistent effort to make administration simpler (for the user); and,
* that failure of policy implementation are treated as public learning opportunities.

There are signs that the political elite in Australia are wary of the NDIS and this does not bode well for stabilising its future. If this is correct, people with disabilities and carers together are the best support for the NDIS as we have all seen how the NDIS has improved the lives of people with disability but also how the NDIS gives carers a sense that what they do is both valuable morally (*eg*., what is good for the person being cared for), but ethically as well (*eg*., that our society (embodied by the NDIA) values carers and what they do) and most critically, doesn’t leave carers substantially worse off. This conjunction, of the NDIS, people with disability and carers together, is politically powerful and enriching for all. That is a future worth the struggle.

## Conclusion

Thank-you again for this opportunity to comment on the NDIS consultation “*Supporting you to make your own decisions*.”

Best wishes,

Peter [redacted], Canberra, ACT

(10 September 2021)

# References

Antaki, C., Crompton, R. J., Walton, C. and Finlay, W. M. L. (2017). How adults with a profound intellectual disability engage others in interaction. *Sociology of Health and Illness*, **39**, 4. (DOI): 10.1111/1467-9566.12500

Nussbaum, M. (2009). The Capabilities of People with Cognitive Disabilities. *Metaphilosophy*, **40**, 3-4.

National Disability Insurance Scheme (NDIS). (2021a). *Consultation Paper: Supporting you to make your own decisions*. Canberra, Australia.

National Disability Insurance Scheme (NDIS). (2021b). *Companion Paper: Supporting you to make your own decisions*. Canberra, Australia.

United Nations Treaty Collection (2006). United Nations Convention on the Rights of Persons with Disabilities: Declarations and Reservations – Australia. (Online): <https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en#EndDec>

**Support for Decision Making consultation submission**

**Name:** Peter (ACT)

**Date and time submitted:** 9/10/2021 6:40:00 AM

**How do you identify:**

* A NDIS participant: No
* A family member, friend or carer of a NDIS participant: Yes
* A NDIS nominee: Yes
* A legally appointed guardian: No
* A disability support worker: No
* A health or allied health worker: No
* A community member: No
* Aboriginal or Torres Strait Islander: No
* Culturally and linguistically diverse: No
* From a rural or remote area: No
* A person with an intellectual disability: No
* A person with a cognitive impairment: No
* A person with a communication disability: No
* A person with a psychosocial disability: No
* Other: No

# **How can we help people with disability make decisions for themselves?**

* Resources: No
* Information: No
* Decision Guides: No
* Having a person help: No
* Other: No

# **Who are the best people to help you (or a person with a disability) to make decisions?**

* Family: No
* Friends: No
* Peer Support Networks: No
* Mentors: No
* Coordinators: No
* LAC: No
* NDIA Partners: No
* Advocates: No
* Service Providers: No
* Other: No

# **What should they do to help with decision-making?**

No answer recorded

# **How can they get better at helping?**

* Getting to know the participant well: No
* Doing some training on decision support: No
* By having resources and information about providing decision support: No
* Other: No

# **How can we make sure the right people are helping?**

* They are chosen by the NDIS Participant as a decision supporter: No
* They value the rights of people to make decisions with support: No
* They are a registered provider: No
* They enable the participant to take risks: No
* Other: No

# **What should decision supporters know about so they can better help people with disability make decisions?**

* Guidelines for decision supporters: No
* Scenarios or Examples: No
* Information Sessions: No
* Support Networks: No
* Other: No

# **Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?**

No answer recorded

## **What worked well?**

No answer recorded

## **What could have been better?**

No answer recorded

# **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: No
* Peer Support Networks: No
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: No

# **Are there different things to consider for people with different disabilities or cultural backgrounds?**

**An intellectual disability:** No

**A disability that impacts how they think, a cognitive impairment:** No

**A psychosocial disability:** No

**A disability that impacts their ability to communicate:** No

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** No

**From the LGBTIQA community:** No

# **How can we help reduce conflict of interest?**

No response recorded

# **How can we help reduce undue influence?**

No response recorded

# **What are your concerns (if any) around people with disability being more involved in making decisions for themselves?**

No response recorded

# **What else could we do to help people with disability to make decisions for themselves? Is there anything missing?**

No response recorded

# **Do you have any feedback on our proposed actions in Appendix C of the paper?**

No response recorded