



**Submission to the Joint Standing Committee on the  
National Disability Insurance Scheme's  
Inquiry into Independent Assessments**

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## **Submission to the Joint Standing Committee on the NDIS**

### **ARC Discovery Project (ARCDP2001100742) *Adjudicating Rights for a Sustainable National Disability Insurance Scheme* Research Investigators:**

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## About Us

The Hopkins Centre, established in 2017 and co-located at Griffith University and Metro South Hospital and Health Service, is Queensland's premier research agency examining rehabilitation and resilience for people with disability. With over 200 research affiliates, including both academics and clinicians, The Hopkins Centre's approach to research involves a distinctive coupling of the voice of lived experience with systems and policy analysis. The Hopkins Centre's work transcends traditional disciplinary boundaries to investigate how to drive improved outcomes for people with severe disability through translating research into effective policies and practice.

The Law Futures Centre was established in 2015 to produce outstanding scholarship that anticipates, innovates, and meets pressing emerging challenges for law and legal institutions in Australia and internationally. Bringing together researchers from law, environmental sciences, international relations, business, health, criminology and humanities, Law Futures Centre members are committed to outstanding collaborative research that harnesses law as a key melioristic tool for shaping a better, more just future.

As academics and researchers from these two Griffith University centres, in drafting this submission we have drawn upon both our individual expertise and some of our preliminary work on a current research project, *Adjudicating Rights for a Sustainable NDIS* (2020-2022), which is funded by an Australian Research Council (ARC) Discovery Project (ARCDP2001100742) grant. The project is described more fully in the Appendix to this submission.

## Summary of Submission

1. There is an insufficient rationale to introduce compulsory Independent Assessments ('IA') as a primary input into planning decisions in the NDIS.
2. The introduction of compulsory IAs may conflict with the Convention on the Rights of Persons with Disabilities (CRPD). Disability rights organisations should be funded to carry out Disability Rights Impact Assessments on any such legislative or policy changes that may impact the rights of persons with disabilities. The 2019 findings of the UN Committee on the Rights of Persons with Disabilities should be fully implemented.
3. The introduction of compulsory IAs are in conflict with the current Objects and Principles of the National Disability Insurance Scheme Act 2013 ('NDIS Act').
4. Compulsory IAs in their proposed current form are not consistent with the 2011 Productivity Commission Report or 2019 Tune Review findings.
5. There is insufficient evidence to suggest that the introduction of compulsory IAs will result in increased equity and consistency in NDIS planning decisions.
6. There is insufficient evidence to support the existence of widespread 'sympathy bias' in participant provided documentation in the NDIS resulting in invalid, inconsistent, or inequitable funding decisions.
7. There is insufficient evidence that compulsory IAs will result in valid planning decisions or will improve transparency of decision-making.
8. The introduction of plan budgets based on IAs without further information about what supports are notionally included in the budget will impede a participant's ability to have proper reviews conducted by the Administrative Appeals Tribunal (AAT).
9. The impact of the IA process on family members must be carefully considered. In addition, there must be transparency about how IAs will inform plan budgets in relation to expectations of the quantum of family care and support that will be provided to a participant as compared to funded care and support.

## Our Submission

Our submission is based on our current research and particularly relates to the use of compulsory IA in planning decisions. In our view, it is important that any changes to the NDIS are consistent with the principles of administrative justice, enhance the rights of people with disability and are consistent with the CRPD.

### ***TOR (a) The development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS***

#### *Rationale for Introducing Independent Assessments*

Although the main rationale for introducing IAs is to redress inconsistencies in decision-making and avoid the unfairness of assessment costs for participants, the critical policy issue at stake here is administrative justice. Are IAs an appropriate tool to deliver consistency, and more so promote the entitlements and rights of people with disability as the NDIS was intended? In any case, the proposed approach based around IAs and functional capacity is based on a misperception that standardisation is the solution to inconsistency. What standardisation can do well is improve efficiencies through a bureaucratic or managerial approach. However, severely restricting discretion in the decision process is likely to impact administrative justice, both procedurally and by way of fair outcomes and the rights of people with disability, as the emphasis is on deciding a budget rather than personalising the assessment across a broad spectrum of complex needs and situations.

Clearly, social policy must manage the unavoidable issue of how to distribute limited resources in a fair and sustainable way, and high-cost areas such as health and disability inevitably involve intense value clashes. Assessment and decision-making of benefits are vital processes for resolving these challenges and it is not an easy task to determine what approach is best. This task is more difficult if the end objective is also contested. The question here is whether IAs are about improving the quality and consistency of decision-making or more about ensuring stronger gatekeeping to control expenditure. A major concern is the impact on procedural justice because of diminished transparency through IAs and a seemingly more implicit rationing approach to determining funding. **IAs will mean that participants will not be fully informed of the reasons behind the funding decision and therefore will have limited evidence on which to base an appeal.** Outsourcing the assessment suggests efficiency and financial objectives are an end goal. Quality and consistency on the other hand involve training, resourcing, and appropriate regulatory safeguards. In this case, the use of key performance indicators (KPI) is likely to be a perverse incentive and lead to a misrepresentation of needs. The regulatory measures to adequately control and monitor conflicts of interest (for example between linked disability provider corporations and corporations appointed to carry out IAs) also require further and careful scrutiny.

The emphasis on functional capacity is problematic given the assumption that functional-based assessments are somehow more accurate. Assessment based on functional capacity is positive in the sense that it stresses an individual's capacity to perform tasks unlike impairment models that emphasize loss. However, it is difficult to see how this can cover all specific domains that are both consistent with a standardised approach and accountable for the variability of disability and life contexts. As a starting point for assessment of level of funding, this displaces individuals' goals and aspirations and diminishes the richness and variability of individuals' lives across personal, social and

economic functional domains. It is not clear how a measure of functional capacity is meaningful without relating it to an individual's life functionings and opportunities, and a thorough understanding of the demands, goals and preferences associated with various life domains. **Alignment with the original ideals of the NDIS and indeed, the CRPD, would require assessment of functional capacity in the context of a meaningful life.**

### *Consistency with the Convention on the Rights of Persons with Disabilities (CRPD)*

Australia ratified the CRPD in July 2008 and the Optional Protocol in 2009. There are three major issues about whether the proposed IA process will meet the objects and aims of Australia's obligations under the CRPD.

- The first is that **there should be funding for rigorous scrutiny of any such changes by independent disability rights groups and Disabled People's Organisations (DPOs) against the CRPD framework**, as per the 2019 findings of the UN Committee on the Rights of Persons with Disabilities (the Committee), considered further below.
- The second is to **ensure that the IAs do not compromise the lifetime approach of the NDIS, investing in people with disability early to improve their outcomes later in life.**
- The third is that **the process of applying for support from the NDIS should itself be a rights-compliant, empowering process, and that rights considerations should be balanced and weighted heavily in decisions about resource constraints.** The Committee and academics have put forth some core, guiding principles to assist States in developing appropriate decision-making support frameworks. Emily Cukalevski summarises these as follows:
  - (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.<sup>1</sup>

The NDIS Act is designed to bring the principles and obligations of the CRPD into Australia's domestic legislation by providing access to nationally consistent funding and support to help people living with disabilities realise their aspirations, and to participate in the social and economic life of the community. The preamble of the CRPD, and the General Principles set out in Article 3, reflect the need for the respect for the inherent dignity, individual autonomy (including the freedom to make one's own choices and the independence of the person); the need for persons with disabilities to be able to participate fully and effectively and be included in society; the need for respect for difference and acceptance of persons with disabilities as part of human diversity; and providing persons with disabilities the opportunity to be involved actively in decision-making processes about policies and

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<sup>1</sup> Emily Cukalevski, *Supporting Choice and Control—An Analysis of the Approach Taken to Legal Capacity in Australia's National Disability Insurance Scheme*, 27 March 2019. Available at <https://www.mdpi.com/2075-471X/8/2/8>, p. 4.

programmes, including those directly concerning them. As DPOs have said for decades: “Nothing about us without us”.

In particular the NDIS Act should bring to life Articles 3 (general principles), 4 (general obligations), 7 (children with disabilities), 9 (accessibility), 19 (living independently and being included in the community), 22 (respect for privacy) and 23 (respect for home and the family).<sup>2</sup> In late 2019, the Committee published its findings and recommendations on its recent review of how Australia is meeting its obligations under the CRPD.<sup>3</sup> The Committee was deeply concerned about the following issues relating to NDIS assessments. They found that:

- Disability assessments under the NDIS are still relying heavily on the medical model of disability;
- The NDIS not providing equal opportunities for older persons with disabilities;
- The NDIS was inaccessible because it is too complicated to access, and did not address the lack of services in remote areas; and
- The lack of sustainable and well-resourced individual & independent advocacy programs.

Some of the Committee’s recommendations for Australia included the following:

- Australia should carry out Disability Rights Impact Assessments on any legislative changes that may impact the rights of persons with disabilities.
- Review disability assessment criteria for support schemes under the NDIS and align them with the human rights model of disability, ensuring adequate support for older persons with disabilities, CALD or Indigenous persons with disabilities, and persons with intellectual or psychosocial disabilities.
- Australia should make the NDIS application and review processes easier for people with a disability to use and make sure that all information is accessible.
- Ensure that all Australians with disabilities have access to ongoing, sustainable and well-resourced individual and independent advocacy programs, especially outside of the NDIS.<sup>4</sup>

### *Consistency with Objects and General Principles of the NDIS Act*

The Objects of the NDIS Act<sup>5</sup> and the Principles which guide action under the NDIS Act<sup>6</sup> clearly indicate that the determination and delivery of supports to people with a disability must support and maximise their choice and control in the pursuit of their own goals. The NDIS Act notes the importance of people with a disability being involved in decision making processes about them. The inclusion of these Objects and Principles in the NDIS Act indicate a planning process that is intended to be individualized

<sup>2</sup> The other relevant treaty provisions are Article 10 of the International Covenant on Economic, Social and Cultural Rights (ICESCR); Articles 2 and 26 of the International Covenant on Civil and Political Rights (ICCPR); and the Convention on the Rights of the Child (CRC), especially Articles 2, 9, 18 and 23.

<sup>3</sup> Concluding Observations: UN Report on Australia’s Review of the Convention on the Rights of Persons with Disability (CRPD), 24 September 2019. Available at <https://www.afdo.org.au/wp-content/uploads/2019/09/UN-Outcomes-Report-on-Australia.pdf>

<sup>4</sup> See Committee recommendations p3. Available at <https://www.afdo.org.au/wp-content/uploads/2019/09/UN-Outcomes-Report-on-Australia.pdf>

<sup>5</sup> *National Disability Insurance Scheme Act 2013* (Cth) (‘NDIS Act’) s 3

<sup>6</sup> NDIS Act s 4 and 5.

and goal responsive. What is reasonable and necessary for one participant, may not be reasonable and necessary for another participant with a similar disability but very different goals, aspirations and circumstances. **The current proposal to use IAs as the ‘primary source of information’ to determine an ‘indicative plan budget’<sup>7</sup> and to delay goal setting until a later planning conversation within a set budget will decrease the choice and control of NDIS participants.** It will result in a move away from individualised planning with the potential for budget ‘capping’ based on ‘profiles’ of participants with similar functional capacity. This is inconsistent with the current Objects and General Principles of the NDIS Act. The absence of individualised goals in the determination of the budget may mean, in reality, there is insufficient funds for supports which would be reasonable and necessary to allow pursuit of individual goals. In short, choice and control and individualised decision-making will be illusory if the budget is wrong, insufficient or is effectively ‘capped’. **While we welcome budget flexibility which allows participants more input into the use of their own ‘personalised’ budget, this should not come at the expense of budget adequacy or transparency in relation to how individual support budgets are determined.**

### *Consistency with Recommendations of Productivity Commission and Tune Review*

The 2011 Productivity Commission Report ‘Disability Care and Support’<sup>8</sup> and the 2019 Review of the NDIS Act 2013<sup>9</sup> (commonly referred to as the Tune Review) are referenced in the relevant proposals<sup>10</sup> and in NDIA and ministerial communications as providing recommendations that support the introduction of IAs. It is true that both these reports considered the role of independent health professionals to undertake functional assessments, and that both reports saw significant value in the use of independent assessors. However, it is inaccurate to suggest that the iteration of IAs as currently proposed are supported by either report.

The Tune Review considered IAs, as proposed in the 2011 Productivity Commission Report, and as developed in the first Independent Assessment pilot (Nov 2018 – April 2019), as appropriate when *offered on a voluntary, opt-in* basis to NDIS participants or potential participants, especially as one way to mitigate financial barriers that exist for people with disability seeking to navigate the NDIS. It is in this form that the Tune Review made Recommendation 7b to amend the NDIS Act to provide discretionary powers for the NDIA to require a prospective participant or participant undergo an assessment. Of utmost significance here is the use of IAs as an *option*; in *certain circumstances*; used at the *discretion* of the NDIA. This is in stark contrast to the current IA framework that IAs become mandated and the only accepted assessment of functional capacity, which then becomes the key assessment used to determine plan budgets.

Although the 2011 Productivity Commission Report recommended the use of independent assessments undertaken by a NDIA approved and monitored pool of allied health professionals, the

<sup>7</sup> DSS, *Information Paper: Improving the National Disability Insurance Scheme*, 24 November 2020, available at [https://www.dss.gov.au/sites/default/files/documents/12\\_2020/information-paper-release-december-2020-final\\_0.pdf](https://www.dss.gov.au/sites/default/files/documents/12_2020/information-paper-release-december-2020-final_0.pdf) (‘Information Paper’). We note that there are some categories of additional fixed budget support where funding may be determined differently including SDA, high cost and complex assistive terminology, home modifications and extensive behavioural support.

<sup>8</sup> <https://www.pc.gov.au/inquiries/completed/disability-support/report>

<sup>9</sup> <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme/review-of-the-ndis-act-report>

<sup>10</sup> For example see Information Paper, n 7 and NDIA Consultation Papers available at <https://www.ndis.gov.au/community/we-listened/you-said-we-heard-post-consultation-reports/planning-policy-personalised-budgets-and-plan-flexibility>



report also repeatedly noted that in undertaking independent assessments, individuals would have scope to involve any/all others ‘who were familiar with the care and support needs of the individual’ in the process and ‘draw upon existing medical reports’<sup>11</sup>. **In comparison to the original proposal, the current IA framework severely diminishes the collaborative assessment process.**

### *Equity and Consistency*

We agree that it is important that there is equity and consistency of general approach in the NDIS planning process and allocation of support budgets. We are very concerned in relation to differential planning outcomes for NDIS participants based on socioeconomic, geographic and other equity background. **We support financial support by the NDIA for assessments of potential participants who could not afford assessments themselves, and clear guidelines that indicate consistent information about functional capacity and other matters that must be provided by all participants to inform the planning process. We do not believe that compulsory IAs for all participants is the most effective way to ensure equity and consistency in NDIS planning.** The current proposals appear to imply that average higher plan budgets for participants in higher socio-economic areas are an indication that those participants are overfunded, such that IAs are necessary to ensure a more appropriate ‘consistent’ potentially lower level of funding for those participants. We have seen no evidence in the current proposals that this is the case. It is more likely that participants in particular categories<sup>12</sup> and in lower socio-economic areas are underfunded due a wide range of well-known barriers such that there should be a focus on mechanisms that will result in enhanced access and funding for those participants. Equity should be achieved by focusing on removing barriers and supporting the most vulnerable participants, so their level of plan funding is enhanced, rather than using a mechanism to lower funding for other participants. **We also submit that while equity and consistency in planning is important, these goals should not be considered in isolation from and more important than choice, control and individualisation of funding which maximizes the rights of people with a disability.**

### *‘Sympathy Bias’*

We note in the various documents supporting the introduction of IAs, references to the existence of ‘sympathy bias’ as a reason to prefer IAs over participant sourced assessments and reports. Standardisation through use of IAs with measures of functional capacity is argued to be a more logical and *objective* approach to guide decision-making to achieve equity and consistency. However, often there is a tendency to overstate the benefits of standardisation to achieve consistency and social-related values such as equity and fairness. Complex decisions such as what is appropriate funding for people with diverse disability-related needs requires a sophisticated process of assessment and a system conducive to good decision-making. Ideally, this process and the system that sits around it should combine processes that derive comprehensive understanding of complex needs and complex contexts with valid assessment mechanisms and clear values to generate transparent decisions.<sup>13</sup>

<sup>11</sup> See p 327, <https://www.pc.gov.au/inquiries/completed/disability-support/report>

<sup>12</sup> For example, Aboriginal and Torres Strait Islander, culturally and linguistically diverse (CALD), and rural and remote participants.

<sup>13</sup> Morland Berit, Ringard Anen, Rottingen John-Arne, ‘Supporting tough decisions in Norway: a healthcare system approach’ (2010) *Int J Technol Assess Health Care* 398.



The assumption that widespread ‘sympathy bias’ is a significant factor causing inconsistency and lack of equity in plans should not be accepted based on current evidence. The study cited in support of the existence of ‘sympathy bias’<sup>14</sup> was small (assessments of 29 people with intellectual disability), based on assessments undertaken at a single residential care site, and involved assessments completed by care workers as opposed to trained experts such as medical professionals, occupational therapists, physiotherapists, clinical and registered psychologists and allied health professionals. All expert assessments (undertaken by an expert employed by a participant or via a professional contracted to the NDIA) can be potentially subject to unconscious cognitive bias. References to eliminating ‘sympathy bias’ suggests a narrow and overly simplistic conception of the mix of overt and latent factors that influence decision-making involving complex needs and the distribution of public resources. Unfortunately, these can be unknowable and extremely resistant. ‘Scientific research suggests that human decision-makers are vulnerable to influences that are much more subtle than those traditionally recognised in our rules, procedures and jurisprudence’.<sup>15</sup> **There is no evidence provided in the proposals that NDIA contracted IAs would be more valid or ‘objective’ than participant sourced assessments or reports.** There are factors in the proposed IA process, for example short time frames, the impact of KPIs required by the NDIA, levels of assessor expertise and training, IA payment mechanisms, and complexity of the IA decision-making task, which may induce bias in the IA process. **There are other more appropriate methods to control the potential impact of bias than the compulsory use of IAs.** These include the impact of existing professional codes of conduct on professionally registered allied health and medical professionals,<sup>16</sup> quality control procedures and mechanisms within the NDIA, and the current ability of the NDIA to carry out its own assessments to supplement participant provided documentation.

***TOR (g) The implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports***

We note that it is intended that the proposals for the use of IAs, particularly in planning, is to improve transparency and consistency of decision-making. The lack of transparency and consistency in NDIS decision making has been noted in numerous reports including the Tune Review and the Joint Standing Committee’s recent Inquiry in relation to NDIS planning.<sup>17</sup> We agree that clear transparency in how funding decisions are made is critical for a fair NDIS which recognizes the rights of all participants and which delivers administrative justice. However, **we are concerned that there is a lack of transparency in the current IA proposals in relation to exactly how IA will be used or translated into the calculation of a budget for supports.** The NDIA has indicated the new approach will result in the replacement of Typical Support Packages as a reference point and will result in a stronger ‘link’ between functional capacity and budget. However, there is a lack of detail as to how budget figures will be calculated from an IA, what forms of support are considered appropriate for particular functional capacity ‘profiles’ and the extent to which information collected during the IA process will

<sup>14</sup> See Independent Assessment Framework available at <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-framework>, which cites Guscia, Harries, Kirby and Nettelbeck ‘Rater Bias and the Measurement of Support Needs’ (2006) 31(3) *Journal of Intellectual & Developmental Disability* 155.

<sup>15</sup> Edmond & Martire, ‘Just Cognition: Scientific Research on Bias and Some Implications for Legal Procedure and Decision-Making’ (2019) 82(4) *Modern Law Review* 633.

<sup>16</sup> See [Australian Health Practitioner Regulation Agency - Home \(ahpra.gov.au\)](https://www.ahpra.gov.au/)

<sup>17</sup> [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Joint/National\\_Disability\\_Insurance\\_Scheme/NDISPlanning](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/NDISPlanning)

be used to 'individualise' a plan budget. There is some reference to general demographic and personal factor information being collected about participants during the IA process (for example informal support, geographic location, life stage transition, age) but the extent to which this information will (or will not) individualise a participant's budget is not presently clear. We support the submissions made by Bruce Bonyhady<sup>18</sup> that the 'evidence to support that IA is fit for purpose and that it will lead to more valid, equitable and consistent planning decisions is missing'. **We submit that there should be no introduction of compulsory IA as the primary input to planning budgets unless and until there is clear evidence that this will produce valid, equitable and consistent planning decisions.** This evidence was not apparent from the results of the evaluation of the first IA pilot which was small, based in a limited geographic area and included participants with a limited range of disabilities.<sup>19</sup> The results of the second larger IA pilot have not yet been released.<sup>20</sup> **There has been an ongoing fundamental focus on evidence-based decision-making in the NDIS and this should continue.** It is also important to note that the recent Auditor General report on "Decision-making Controls for NDIS Participant Plans"<sup>21</sup> found quality assurance issues in relation to NDIA decision-making and noted the "NDIA does not yet have appropriate controls to ensure that supports in participant plans are 'reasonable and necessary'". Lack of current quality controls in decision-making is another reason to be cautious of the adoption of new mechanisms as a primary factor in plan budgets. In addition, the use of IA in determination of reasonable and necessary supports as proposed will be a very significant change of direction for the NDIS and will not build on the existing guidance on determining reasonable and necessary support that has emerged from the AAT and in major reviews such as the Tune Review.

#### ***TOR (i) Opportunities to review or challenge the outcomes of independent assessments***

At present, it is proposed that IAs themselves will not be directly reviewable by the AAT or by another external or independent review mechanism such as a medical panel. We are concerned that there will be an absence of an external or independent review of IA particularly given recent AAT decisions which have found inadequacy of assessments conducted on behalf of the NDIA.

The current proposals note that it is intended that planning decisions will remain reviewable in the AAT. However, in practice **we suggest it will be very difficult for participants to challenge or review planning decisions about general supports where they have only been provided with an overall budget amount.** This is particularly so given, as we note above, it remains unclear how IA will inform the production of a plan budget for an individual participant. In the absence of a breakdown of what supports have and have not been notionally included in the plan budget (outside of fixed budget items) participants will not be able to identify error or grounds for review apart from general dissatisfaction with the total budget figure. **Planning decisions will become opaquer to participants than at present. This outcome will be in direct contradiction of recent reviews which have noted the**

<sup>18</sup> [Independent-Functional-Assessment-An-Analysis-of-the-Proposed-Approach-by-the-NDIA-Final-22-February-2021.pdf \(unimelb.edu.au\)](https://www.unimelb.edu.au/files/Independent-Functional-Assessment-An-Analysis-of-the-Proposed-Approach-by-the-NDIA-Final-22-February-2021.pdf). Bonyhady notes a range of matters which are unclear in relation to how IAs will be used to determine planning including weighting and combination of assessment tools, accuracy of judgment of assessors, typical population ranges, validity, reliability and accuracy of the use of AI to inform planning decisions.

<sup>19</sup> 513 voluntary participants only with Autism Spectrum Disorder, Intellectual Disability or Psychosocial Disability in metropolitan NSW.

<sup>20</sup> [Independent assessment pilot | NDIS](https://www.ndis.gov.au/working/assessments/assessments/pilot). There is a suggestion in the pilot evaluation that the plan values produced with IA did more closely align with reference packages but this does not necessarily mean that such plan values validly estimated individualised supports for individual participants.

<sup>21</sup> <https://www.anao.gov.au/work/performance-audit/decision-making-controls-ndis-participant-plans>

need for much more information to help participants understand planning decisions. Transparency will decrease rather than increase.

### ***TOR (I) Any other related matters***

#### *The Role of Families and Reasonable and Necessary Support*

Mimicking the tone of the Universal Declaration of Human Rights<sup>22</sup> (UDHR) and CRPD, the Tune Review also explicitly states that “a key principle of the NDIS is that all people with disability have the same fundamental rights as all members of Australian society to participate in the social and economic life of the community and to make their own choices and decisions”.<sup>23</sup>

The introduction of compulsory IAs positions families in the role of advocate for the rights of family members with disability. Compulsory IAs mean that family members of people with disability, particularly those that provide care, will once again, be required to advocate for what constitutes a reasonable and necessary support. **The expectations placed on family members to restate the experiences, levels of disability and the impact of their family member’s disability will likely be required in order to gain an authentic assessment of supports. This clearly supports a deficit model of storytelling in order to gain adequate supports, which not only places additional expectations on the family member<sup>24</sup> as advocate, but also has the potential to add tension to the relationship between the person with disability and their family member.**

The recent Joint Standing Committee’s inquiry on NDIS Planning identified that there continues to be over reliance on family members to provide the support required for NDIS participants in planning. It is also clear that there is a perceived availability of family members to provide support, and in some of these cases, there is no indication of previous family supports or alternatively these family supports (eg. ageing parents) are no longer able to undertake the role of caregiver. The result of these assumptions can have substantial impacts on participants. For people who rely on a family member to provide both care and advocacy, the implementation of compulsory IA places extreme pressures on these family members to competently and clearly advocate for the appropriate outcome of the IA. There are additional inequities placed on family members and people with disability who are from Aboriginal and Torres Strait Islander backgrounds or Culturally and Linguistically Diverse (CALD) backgrounds. While there are concerns about the appropriateness of IA, the meanings of disability in Aboriginal and Torres Strait Islander and CALD cultures must be also considered.<sup>25</sup> Experiences of racism, language barriers and cultural barriers may impact on the family’s capacity to advocate during an IA.

Family members have previously noted the need for ongoing advocacy around the decisions made by professionals and NDIS planners that impact on the supports that participants receive. It is evident through varied submissions to this Joint Standing Committee, the recent NDIS Planning inquiry, the Tune Review, and in AAT cases, that family members, particularly parents, play a significant role in

<sup>22</sup> <https://www.un.org/en/about-us/universal-declaration-of-human-rights>

<sup>23</sup> See p. 24 <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme/review-of-the-ndis-act-report>

<sup>24</sup> Venning et al., ‘Adjudicating reasonable and necessary funded supports in the National Disability Insurance Scheme: A critical review of the values and priorities indicated in the decisions of the Administrative Appeals Tribunal’ (2020) 80 *Aust J Publ Administration* 97. <https://doi.org/10.1111/1467-8500.12438>

<sup>25</sup> Hollinsworth, ‘Decolonising Indigenous Disability in Australia’ (2013) 28 (5) 5 *Disability & Society* 601.

advocating for the needs of NDIS participants. **The additional expectations and strains placed on family members of people with disability must be considered in the decision to implement compulsory IA.**

**We also have significant concerns how the IA process will account for and make assumptions about the level of family support that can be provided to a participant and accordingly how much paid support will be provided in a plan budget. This will be less transparent in the new IA process.** For example, it is possible that inappropriate assumptions may be made on the basis of an IA about how much care can in fact be provided by family members who are elderly, have paid work obligations, or who wish to work to avoid financial loss. In addition, we would be concerned that (in absence of further detail about how IA functional assessment translate to plan budget) inappropriate and general stereotyping about family care obligations may occur, which will particularly impact female carers.

We stand willing to give evidence to the Committee if required.

Kind regards,

Kylie Burns, Michele Foster, Susan Harris Rimmer, Eloise Hummel and Alyssa Venning

## APPENDIX

### **About the ARC Project *Adjudicating Rights for a Sustainable National Disability Insurance Scheme* (ARCDP2001100742)**

By enhancing the visibility and transparency of decision-making processes and priorities, and promoting informed public discussion, this project will contribute to making the National Disability Insurance Scheme a fair and sustainable scheme, and an international exemplar. The study involves three phases conducted over three years (2020 – 2022) and employs a multidisciplinary, translational design incorporating analysis of social, policy and legal frameworks, qualitative interviews, analysis of administrative data and qualitative case study methods to develop both a broad national understanding of dominant frames surrounding the administrative justice decisions and concepts of justice; and a more nuanced understanding of administrative justice as experienced by participants.

The project will highlight the power and justice effects of the administration of the NDIS, including what principles and values serve as dominant justifications for reasonable and necessary support, areas of contestation with choice and control, and the discrepancies in how administrative justice is viewed. The findings will contribute to a better understanding of which participants the NDIS is failing and contribute to a critical debate about the values guiding funded support decisions and fairness outcomes.