



The Impact of Independent Assessments on the Parkinson's Community:

A response to the National Disability Insurance Scheme Consultation paper: Access and Eligibility Policy with independent assessments (released Nov 2020)

Submission prepared and submitted by **Parkinson's Victoria**

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Parkinson's Victoria acknowledge the positive impacts that the National Disability Insurance Scheme (NDIS) has had on the Parkinson's Community. Whilst we support the NDIS' pursuit of improved equity and consistency within the scheme, the Independent Assessment (IA) framework and proposed implementation raises significant concerns.

'Young-onset' Parkinson's:

Empirical research in Australia estimates that the incidence of Parkinson's disease currently ranges between 84,000 (lower end) and 212,000 (higher end), something that is conservatively estimated to grow by 79% from 2014 to 2034. More than 27,000 Victorians live with Parkinson's disease (Ayton et al, 2018), and while the condition is more common in people over 65 years of age where prevalence is greater than 82%, 18% are of working age (Deloitte Access Economics Report, Living with Parkinson's Disease, 2015). For those of working age, approximately 20% will be in later stages of disease where severe disability occurs before the age of 65 years. It is therefore estimated between 3-5% living with Parkinson's disease will be in scope for the NDIS.

Parkinson's symptomatology is complex and progression continues despite medication therapy. Importantly, it doesn't just affect movement. Non-motor symptoms including pain, autonomic dysfunction, anxiety, depression, fatigue, communication and swallowing problems, sleep disturbance and cognitive decline, can be equally incapacitating. The functional impact of these motor and non-motor symptoms largely depends on disease progression and response to medication therapy. Daily, and even hourly fluctuations in symptoms and function are common which can result in variable capacity to perform daily activities and sustain an individual's expected and valued responsibilities or roles. Access to suitably experienced health professionals can assist in managing the challenges of Parkinson's ([Parkinson's Victoria website; professional support](https://www.parkinsonsvic.org.au)). This is also the case for those with a rare Atypical Parkinson's condition, with average age of diagnosis typically in the sixties, and for which there is a poorer prognosis and more rapid symptom progression (McFarland 2016).

Ensuring that people with Parkinson's can continue to access age-appropriate support is important for improving individual outcomes (Deloitte Access Economics Report, p. 105). In its guiding principles, the NDIS Act (2013) emphasises the importance of participant 'choice and control', providing 'certainty' that participants will receive care and support over their lifetime (NDIS Act, 2013; Part 2; 4). The changes proposed in this paper raise specific concerns for how the Parkinson's community will continue to access and retain important NDIS supports. Our concerns are detailed in the below submission.

Independent Assessors:

Whilst the rationale behind the implementation of the Independent Assessment (IA) framework is understandable (equity of access, fairness, consistency and scheme sustainability), concerns remain surrounding its proposed implementation. IAs are to be implemented from the middle of 2021 for all applicants over 7 years of age (p. 3). However, Parkinson's Victoria has significant concerns that this model has not been fully explored or the impact upon people with complex and changing progressive neurological illness understood. The Tune Review (2019) specifically stated "the NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments" ([Tune Review 2019](#), p. 67).

Implementation is being modelled on outcomes of a pilot of only 600 participants, not representative of those with physical or complex disability ([Independent assessment pilot | NDIS](#)). The second pilot, whilst more inclusive of physical disability and greater in numbers, is still incomplete ([The second independent assessment pilot | NDIS](#)). With participation in the pilots reliant on volunteers, pilot results are not necessarily representative of those who have communication issues, complex needs or are unable to advocate for themselves.

Our organisation represents the needs of people living with Young Onset Parkinson's, which accounts for 20% of our cohort. We are aware of the relative 'rarity' of this presentation, which when combined with the highly individual nature of presentation creates challenges in clinical assessment. The proposed changes state that the IAs will be performed by 'trained experts' (p. 7). However, given the complexity of Parkinson's and Atypical Parkinson's conditions, it is questionable as to whether an Independent Assessor will have the specialised knowledge in order to fully explore an applicant's functional capacity. If the health care professional performing the assessment does not understand complex and fluctuating neurological symptoms and disease progression, the assessment outcome is unlikely to be reflective of the actual situation. This will be further compromised when the individual has communication issues and is unable to express how their condition impacts their function.

NDIS principles of 'choice and control':

Despite NDIS' principles of 'participant choice and control' (Part 2, section 3 (1e) [National Disability Insurance Scheme Act 2013](#)), applicants and current NDIS participants will be required to have an assessment completed by an unknown Independent Assessor, rather than by their regular health care providers (who best understand their functional capacity and intricacies of their condition). Whilst the paper highlights that in some circumstances, applicants' usual health care providers can be consulted or additional information requested (p.20), there is no information in the paper pertaining to when and how these requests would be generated and the weighting of this additional information in the eligibility process.

Participants will also be significantly limited in choice of organisations that provide the IA service, or which discipline the assessor represents. This is especially so in rural areas, where successful IA tenders are likely to be from large organisations, covering considerable geographical areas. Rural

participants will be further disadvantaged by geographical limitations and the likely completion of telehealth assessments, regardless of participant choice and potential communication issues.

The 'independent' nature of an NDIA-contracted assessor also remains questionable which raises concerns surrounding the assessment process. Participant feedback raised in the Tune Review highlighted that "NDIA staff do not understand disability or appreciate the challenges people with disability face as part of everyday life" ([Tune Review 2019](#) p. 28). Considering the complexity of progressive neurological conditions such as Parkinson's and Atypical Parkinsons, there is significant doubt that Independent Assessors will consistently have the specialised knowledge and expertise in these conditions in order to improve participant confidence in the scheme. The unfortunate outcome of having inadequately experienced assessors, is more likely to lead to the inappropriate denial of NDIS access or an allocation of funds that is unsuitable for the participant's functional needs.

Duplication of Assessment:

Parkinson's Victoria acknowledges the financial burden that many prospective participants experience when compiling evidence in preparation for NDIS access and planning decisions. Despite the financial advantage of having a 'free' assessment, arranged by the NDIS, applicants will still require evidence of permanence from their medical team. The current IA model does not replace the need for individuals to continue to require assessments from relevant health professionals in order to direct their care. Independent Assessors will be unable to provide recommendations on support needs or "to provide any clinical or other professional advice to participants or prospective participants" (pg.7 [IAP Tender Statement of Work revised 3 June 2020](#)). Hence, individuals will still need to pursue assessments from relevant health professionals in order to obtain clinical advice and recommendations on supports. This is likely to cause unnecessary duplication of assessments, additional costs and potential distress to the participant. This is even more pertinent in the Parkinson's community where symptoms of anxiety and depression are significantly common.

The paper highlights the potential frequency of Independent Assessments throughout a participant's NDIS journey (at different life-stages and at least every 5 years; p. 11) as well as their ability to inform an eligibility reassessment decision (p. 22). Incorporating regular independent assessments has the potential to create uncertainty, fear and disengagement and appears contradictory to the NDIS Act's intention of providing 'certainty of care and support' throughout one's lifetime (Part 2, section 4 (3) NDIS Act, 2013).

Suitability of Assessment Tools and Parkinson's:

NDIA specify that "new and existing NDIS participants will undertake three or four" tools from the proposed suite of assessment tools as part of their independent assessment ([The independent assessment toolkit | NDIS](#)). However, from the 6 core assessment tools currently highlighted in the proposed suite of assessments, only two have relevance for someone with a complex disability such as Parkinson's Disease; the World Health Organisation Disability Assessment 2.0 ([WHODAS](#)) and the Craig Hospital Inventory of Environmental Factors ([CHIEF](#)). This paper claims the assessments will allow them to find out about 'good days and bad days', and highlights that individuals can elect to have the 3 hour assessment performed over a number of appointment times (p.18). Whilst we acknowledge the NDIA's attempt to cater for variations in function, the selected assessment tools are checklist-based and, as such, do not have sufficient detail to provide a full and complete picture for someone with Parkinson's or similar condition. This is particularly the case for individuals who fluctuate on a daily or even hourly basis and for which, a 'point-in-time' assessment should not form the basis for significant decisions surrounding eligibility and allocation of funds.

There is discussion in the paper about an opportunity for informal chat (p.18) to aid the independent assessor and applicant / participant in getting to know each other, but how these conversations are interpreted and weighted by the NDIA is not made clear.

Similarly, there is concern that reassessments throughout an individual's NDIS journey utilising these assessment tools may not be adequately reflective of symptom progression and result in unrealistic budgets, inadequate supports and potentially unnecessary reassessments of eligibility.

Functional Capacity and Parkinson's:

Conditions such as Parkinson's and Atypical Parkinson's require clinician knowledge surrounding the complex nature of motor and non-motor symptoms when evaluating an individual's functional capacity. A functional capacity assessment requires skills in observation, interviewing, professional judgement, selection of appropriate and relevant assessment tools as well as consideration of historical events and fluctuations in function. It is a comprehensive process incorporating perspectives from the individual, family, carers, specialists and health professionals as well as the environmental context. A functional capacity assessment performed by those suitably trained in its application should generate recommendations representative of an individual's support needs and direct realistic budget estimates.

Despite this, in the original tender for the Independent Assessor Panel, it highlights that Independent Assessors will not provide recommendations on the support needs of participants or prospective participants (pg.7 [IAP Tender Statement of Work revised 3 June 2020](#)), yet this paper proposes that participants will receive a *personalised* plan budget, *informed* by their Independent Assessment (p. 11). These discrepancies give rise to concerns surrounding how personalised budgets will be established if primarily based on scores obtained from a 'point in time' assessment, with limited ability to capture the historical context or potential for regular fluctuations in function.

Conclusion:

Parkinson's and Atypical Parkinson's conditions are highly complex. Having access to Health Professionals with sufficient experience and knowledge in management of these conditions is already challenging. Given that this community experience motor fluctuations, complex symptomatology, and progressive deterioration in function, there is concern that functional capacity will be inadequately captured using the proposed model of IA. The results of these IAs have potential to categorise individuals inappropriately, establish unrealistic budgets and generate stressful, and inappropriate revisions of eligibility which may inevitably lead to participant disengagement and risk of harm.

Parkinson's Victoria therefore suggest that further evaluation and stake-holder consultation is required to explore other methods for improving equity and consistency.

Some suggested pathways to improve the proposed access and eligibility process include:

- a) Ensuring functional capacity assessments are performed by suitably trained health professionals (eg. Occupational Therapists).
- b) Providing assessors the opportunity to perform more comprehensive evaluations to supplement the standardised tools and permitting professional recommendations to help establish client goals and guide appropriate eligibility and budgeting decisions.
- c) Re-allocate Government funds towards provision of specialised training or an endorsement program for health care professionals, enabling applicants and participants greater choice and control.
- d) Complete further evaluation of the proposed assessment tools with the progressive neurological cohort.

References:

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NDIS (2020) Independent Assessment Pilot; [Independent assessment pilot | NDIS](#)

NDIS (2020) The Independent assessment toolkit; [The independent assessment toolkit | NDIS](#)

NDIS (June, 2020) Attachment 1 – Statement of Work, Request for Tender; Independent Assessment Panel Reference Number – 1000724626. [IAP Tender Statement of Work revised 3 June 2020](#)

NDIS (2020) The second Independent Assessment Pilot [The second independent assessment pilot | NDIS](#)

Parkinson's Victoria website: Professional support <https://www.parkinsonsvic.org.au/parkinsons-and-you/professional-support/>

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