

## **The impact of proposed changes to Planning policy for Personalised Budgets and Plan Flexibility on the Parkinson's Community:**

**A response to the National Disability Insurance Scheme Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility (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 proposed process for generating personalised budgets as well as the planned methods for monitoring ongoing eligibility raise 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](#)). 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) emphasise that participants, families and carers should have 'certainty' they 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, especially given the heterogeneous nature of their condition. Our concerns are detailed in the submission below:

**Ability of 'personalised' budgets to accommodate complex and progressive needs:**

It remains unclear as to how a 'personalised' budget will be established following the Independent Assessment (IA). The paper indicates that the data obtained through the IA will be norm-referenced with other participants sharing similar 'scores' and levels of functional capacity (p. 13). This notion of 'grouping' individuals based upon outcomes obtained from point-in-time, checklist and score-based assessment tools, raises significant concerns surrounding the National Disability Insurance Agency's (NDIA's) understanding of disease-specific implications on function. Parkinson's and Atypical Parkinson's conditions are complex and heterogeneous. Determining functional capacity requires specialised knowledge and understanding of the complex symptomatology and potential for fluctuations and progressive deterioration in function. Establishing the impact of disease based upon point-in-time, 'disability neutral' assessment tools creates significant potential for this cohort to be allocated a budget that is inappropriate for need, or more importantly, the potential to be erroneously denied NDIS eligibility.

**Ensuring appropriate budget allocations:**

Historically, NDIS plan budgets have been established in *response* to an individual's life goals. Yet the proposed IA format does not include any recommendations for discussion or documentation of a participant's goals, aspirations or historical context. This paper specifies that "a participant will use their personalised budget to pursue their goals, and meet their disability-related support needs" (p.17), yet their budget is established *before* the individual has an opportunity to discuss their goals and needs. With draft budgets being informed by the results of the IA and with Independent Assessors having no opportunity for clinical recommendations, there is significant potential for inappropriate budget allocation and the subsequent hindrance of the participants' goals and needs.

The paper stipulates that draft budgets can only be changed in 'specific circumstances', with the reliance on the delegate to initiate the request for alterations to the allocated budget. Whilst it has been made clear that Independent Assessors will be health care professionals, there is insufficient information surrounding the credentials and expertise of NDIA Delegates and planners. As a result, we have little assurance that there will be suitable opportunity for draft budgets to be appropriately analysed and adjusted.

If a draft budget excludes an allocation of funds for high-cost supports such as complex assistive technology or home modifications (p.13) and if a delegate neglects to determine and explore this shortfall, individuals with complex progressive neurological conditions, such as Parkinson's and Atypical Parkinson's, may have inadequate funding allocations for essential equipment and home modifications. The implications of this can be the difference between someone remaining in their own home or entering supported disability accommodation, particularly when individuals require timely access to funds without the need to jump through bureaucratic hoops.

Of similar concern for those with rapidly progressing neurological conditions, is the proposal the “funds can’t be over-drawn above the funding level released into a plan at each interval” (either monthly or quarterly); (p. 20). This has the potential to result in temporary periods of inappropriate supports and subsequent risk to participants and carers.

#### **Implications of regular ‘check-ins’ and instigation of Independent Assessments:**

The paper proposes regular ‘check-ins’ (p. 21) that will occur at intervals decided by the delegate. These check-ins have potential to initiate IAs. Given that the IA model can impact on a participant’s eligibility to remain an NDIS participant, this regular check-in process may instigate participant feelings of uncertainty and fear, and exacerbate anxiety in participants with Parkinson’s in the lead up to these appointments.

The NDIS Act 2013 states that “People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime” (Part 2, Section 4 (3) [National Disability Insurance Scheme Act 2013](#)). Yet, the incorporation of regular IAs throughout a participant’s NDIS journey (including during plan reassessment – p. 23) contradicts this ‘certainty’ of support.

#### **Reviewable decisions:**

Unfortunately, this paper highlights the fact that participants will not be able to request a new IA if they disagree with the IA results. 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 and the draft budget will be inappropriately calculated. This will be further compromised when the individual has communication issues and is unable to express how their condition impacts their function. Having no opportunity to dispute the assessment results or request a reassessment by an alternative assessor is unfair and has implications of inappropriate allocation of funds or inappropriate re-evaluation of NDIS eligibility.

#### **Conclusion:**

The process for establishing a personalised budget remains unclear. Without consideration of a participant’s life-goals and by determining a draft budget based upon ‘scores’ from the IA outcome, it appears unlikely that a participant’s budget will reflect their actual needs. For those with progressive neurological conditions and complex needs, as well as potential for significant mental health symptoms, the proposed model is likely to generate further anxiety, uncertainty and avoidance, putting this clientele, and their carers, at potential risk for harm.

Parkinson’s Victoria therefore suggest that further evaluation and stake-holder consultation is required to explore other methods to improve simplicity and fairness.

Some suggested pathways to improve the proposed planning policy for personalised budgets and plan flexibility include:

- a) Further liaison with organisations representative of progressive neurological conditions to establish a less intrusive process that acknowledges disease progression and doesn’t require frequent justification (and IAs) that supports and budgets remain warranted.

- b) Ensuring functional capacity assessments (IAs) are performed by suitably trained health professionals (eg. Occupational Therapists) to more appropriately inform budget decisions.
- c) Providing assessors the opportunity to perform more comprehensive evaluations to supplement the standardised tools and permit professional recommendations to help establish client goals and guide appropriate budgets.
- d) Ensure delegates have the appropriate credentials and health experience to ensure they appropriately evaluate and scrutinise draft budgets to ensure they are appropriate for need.
- e) Ensure participants can access sufficient funds, in a timely manner, due to rapid disease progression or unexpected change in circumstances (even if funds have been already exhausted for an allocated funding interval).
- f) Re-consider the criteria to ensure participants can request a review of IA results or undergo reassessment if desired, particularly in the situation where IA expertise is in question.

### **References:**

Ayton, D., Ayton, S., Barker, AL., Bush, AI and Warren, N. (2018). Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism & Related Disorders*. October 2018.

Deloitte Access Economics; Living with Parkinson's Disease, An updated economic analysis 2014, Parkinson's Australia Inc.

McFarland, N (2016) Diagnostic Approach to Atypical Parkinsonian Syndromes *Continuum (Minneapolis)* vol 22, 4 Movement Disorders; 117-42

National Disability Insurance Scheme Act (2013) [National Disability Insurance Scheme Act 2013](#)

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