



**Submission to the  
Productivity Commission**

**Review of National Disability  
Insurance Scheme Costs**

July 2017

## Contents

Executive Summary .....	3
Introduction .....	5
Comments on Draft Recommendations, Findings and Information Requests .....	6
Draft Finding 2.1.....	6
Draft Finding 2.4.....	6
Information Request 3.2.....	7
Information Request 4.2.....	8
Draft Recommendation 4.1 .....	8
Draft Recommendation 4.2 .....	9
Draft Finding 5.1.....	10
Draft Recommendation 5.1 .....	10
Draft Recommendation 5.2 .....	11
Draft Finding 7.1.....	12
Draft Recommendation 7.1 .....	12
Draft Recommendation 7.2 .....	12
Information Request 8.1.....	13
Information Request 8.2.....	13
Draft Recommendation 9.5 .....	14
Information Request 9.1.....	14
Other Issues not identified in findings and recommendations .....	15
Early Intervention.....	15
Impact on mainstream services .....	15
Boundaries between health and disability services.....	15
Specialist Support and Information Services .....	15
Low Utilization rates.....	16
Background .....	17
Parkinson's Australia .....	17
Parkinson's.....	17

## Executive Summary

Parkinson's Australia welcomes the opportunity to provide feedback to the productivity Commission on the *National Disability Insurance Scheme (NDIS) Costs Position paper*.

Parkinson's Australia believes that the National Disability Insurance Scheme (NDIS) has the potential to positively transform the lives of those members of the Parkinson's community who are eligible to access the scheme. It is also recognised that the current phase of the scheme presents very substantial challenges as the number of participants rapidly increases and the geographic coverage spreads.

Parkinson's Australia considers that implementation of the scheme to date has been flawed and has caused significant frustration for many participants and service providers.

There is also evidence emerging that people with Parkinson's who may not be eligible for the NDIS because of age or the nature of their disability are being 'left behind' and that specialised support services that would have been available to them pre NDIS are no longer available or at risk of closure. Parkinson's Australia remains hopeful that continued review and refinement of the NDIS will deliver improvements in access and responsiveness for those people living with Parkinson's throughout Australia.

In this submission the recommendations, findings and information requests relevant to the Parkinson's community have been highlighted and responses and information provided.

A summary of the recommendations includes:

- That the geographic rollout of the NDIS proceed as originally planned by the NDIA and that, where necessary, additional resources be provided particularly in the period leading up to the rollout in an area to assist participants and disability service providers understand the requirements of the NDIS and to provide them with pre-planning support.
- That the NDIA should implement approaches that ensure that eligibility requirements are interpreted in a consistent way and plans that meet the needs of the participants are developed.
- That Parkinson's be included on List A where an applicant with Parkinson's has a specified level of symptom manifestation and disability as measured on an internationally accepted and validated rating scale.
- That the NDIA enhancing the role of LAC's to approve plans would provider better and quicker decision making.
- That the planning process be reviewed to:
  - Enable minor changes to plans without triggering a full plan review
  - Move to an opt-in approach for phone planning
  - Provide better support and information to participants about the planning process particularly in the pre-planning stage and well before the rollout of the scheme to new areas.

- That the NDIA should ensure that planners who are working with people with Parkinson's have a good knowledge and understanding of the progressive neuro-degenerative conditions and relevant qualifications and/or substantial experience in disability services or health care.
- The ILC program should be reviewed, enhanced and accelerated to ensure that all Australians, not just those eligible for the NDIS, with a disability can link to appropriate services and support in their community. Consideration should be given to longer term contracts, funding for ongoing capacity particularly for services with a specialised knowledge of, and who support for people with, chronic conditions.
- That an evaluation of the impact of the NDIS on the broader disability, health and aged care sectors should be undertaken to determine whether there have been adverse and unintended consequences on these sectors as a result of the implementation of the NDIS and what impact this has had on the ability of Australians with a disability, particularly those not eligible for the NDIS, to receive the support they require to:
  - maintain a good quality of life
  - remain as independent and productive members of their communities.
- That current organisational providers of services and support to people with chronic conditions have a role and capacity to educate, support and develop the disability workforce and it is recommended that they be seen as a resource that can be used and supported by the NDIA and government to address workforce gaps.
- That all levels of Government engage with the disability sector to ensure continuity of services for people not eligible for the NDIS and that information on the approach, including details of how services will be supported and funded, be publicly available.
- That support coordination be included in all plans for people living with progressive neurological conditions.
- The crucial role of disability and disease specific support organisations in educating, informing and supporting both people with a disability and service providers be recognised and supported by the NDIA.
- NDIA should consider implementing a systematic approach to continuous quality improvement based on innovation, rapid-cycle testing in the field, and spread to identify and implement improvements in processes, quality and value.
- That an early intervention program for people living with Parkinson's who may not meet the requirements to demonstrate substantially reduced functional or psychosocial capacity be implemented to assist them remain in the workforce and/or remain independent in the community.
- That the NDIA, Federal, State and Territory Governments to act to ensure that capacity, skills and knowledge is not irretrievably lost with the sector as a result of reduced support and funding for mainstream services.

## Introduction

The Productivity Commission has sought feedback on the position paper *National Disability Insurances Scheme (NDIS) Costs*. Parkinson's Australia as a part of the Neurological Alliance Australia (NAA) developed a joint position paper *People with progressive neurodegenerative diseases in the NDIS* which was provided to the Commission in March 2017. The NAA Position paper made the following recommendations:

1. *Improved pre-planning support for people with a progressive neurodegenerative disease;*
2. *NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease;*
3. *Mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease; and*
4. *The needs of people with a progressive neurodegenerative disease be addressed in the Productivity Commission's upcoming Review of NDIS Costs.*

This submission builds on the NAA submission and provides input to the various issues, findings and recommendations made in the position paper.

The Productivity Commission have noted that on the whole that the NDIS does provide consumers with services and supports that assist in improving their quality of life. Feedback received by Parkinson's Australia indicates that, whilst there are many issues with the NDIS and areas of the NDIS operations that can be improved, this is, overall, a reasonable observation.

Notwithstanding that the NDIS can provide valuable support, many report that the initial processes of determining eligibility and then planning can be very difficult and can result in significant frustrations for consumers and their carers. This is further compounded as it has been reported that NDIS planners/delegates knowledge and capability is very varied and often they have poor knowledge of progressive neurological conditions and may not even meet face to face with the client. It has also been reported that planners are under pressure to meet volume targets and that this is impacting on their ability to deliver good quality plans. This all results in some not being able to access the scheme as their disability is incorrectly assessed and not considered to cause substantially reduced functional capacity as required in *National Disability Insurance Scheme Act 2013* or having plans that do not adequately address their needs or having to go through multiple planning sessions.

## Comments on Draft Recommendations, Findings and Information Requests

Comments are provided on the relevant draft findings, recommendation and information requests below.

### Draft Finding 2.1

*The scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious. It risks the National Disability Insurance Agency (NDIA) not being able to implement the NDIS as intended and it poses risks to the financial sustainability of the scheme. The NDIA is cognisant of these risks.*

Whilst it is recognised that the rollout of the NDIS is ambitious there should be no question of slowing the rollout but instead early action needs to be taken and additional resources provided to ensure the on time and successful rollout of the scheme. Any slowing of the rollout may disadvantage those people living in areas which do not already have access to the full NDIS.

Where necessary, additional support and resources be provided particularly in the period leading up to the rollout in an area to assist participants and disability service providers understand the requirements of the NDIS and to provide them with pre-planning support to assist with their smooth transition into the scheme.

### Draft Finding 2.4

*Early evidence suggests that the National Disability Insurance Scheme is improving the lives of many participants and their families and carers. Many participants report more choice and control over the supports they receive and an increase in the amount of support provided. However, not all participants are benefiting from the scheme. Participants with psychosocial disability, and those who struggle to navigate the scheme, are most at risk of experiencing poor outcomes.*

Whilst for some the NDIS is improving their quality of life and access to support, many people still report significant frustrations with the NDIS both in being considered as eligible or having appropriate care plans developed and implemented. Parkinson's Australia is aware of cases where consumers with similar levels of disability and needs have very different outcomes in having their eligibility accepted by the NDIS or appropriate plans developed and approved.

Depression, anxiety and mild cognitive impairment affecting executive function are common symptoms of Parkinson's. This impacts on motivation to self-refer and identify supports which would be beneficial. It also impacts on their ability to understand the requirements of the scheme, to establish eligibility and to develop plans that address their needs.

Parkinson's Australia is aware of an example where an NDIS representative has visited a Parkinson's support group and actively discouraged people with Parkinson's from applying to the scheme and has told them that Parkinson's is not eligible.

The NDIA should examine approaches to ensure that eligibility requirements are interpreted in a consistent way and that effective plans are developed that meet the needs of participants. The NDIS should be structured so that it is responsive to changes in participant needs particularly for participants who have progressive degenerative conditions such as Parkinson's and related conditions which in some cases can progress and change very rapidly. These approaches should recognise the valuable role of carers, service providers and other support people that have the knowledge and experience to inform the development of an appropriate plan. NDIA should also ensure that staff working with people with Parkinson's have a good understanding and knowledge of the condition and, in particular, its complex, progressive and increasingly disabling impact on those diagnosed and understand that it is very much more than just “the shakes” but a condition that impacts all body systems including cognitive and affective nervous systems.

### Information Request 3.2

*The Commission is seeking feedback on the benefits and risks of maintaining ‘List A — Conditions which are Likely to Meet the Disability Requirements in section 24 of the NDIS Act’. In particular:*

- *to what extent does List A reduce the burden for people with permanent and significant disability of entering the National Disability Insurance Scheme under the disability requirements?*
- *is there any evidence that people who do not meet the disability requirements are entering the scheme under List A?*

Whilst Parkinson's Australia is unable to comment on the current operation of List A, many people living with Parkinson's have reported that there is a significant burden in providing information to the NDIA in support of their applications.

It is recommended that Parkinson's be included on List A where an applicant with Parkinson's has a specified level of symptom manifestation and disability as measured on an internationally accepted and validated rating scale such as the Unified Parkinson Disease Rating Scale (UPDRS) and Hoehn and Yahr rating scales which are administered by trained movement disorder clinicians. The listing of Parkinson's would be similar to some of the other conditions included on the list (Cerebral Palsy, Intellectual Disability and Autism) which include rating scales and would reduce significantly the burden placed on people living with Parkinson's. It is not recommended that simply because a patient has not undergone an assessment, or that the patient does not meet the strict requirements of a rating scale, that they be automatically excluded from the scheme.

## Information Request 4.2

*Should the National Disability Insurance Agency have the ability to delegate plan approval functions to Local Area Coordinators? What are the costs, benefits and risks of doing so? How can these be managed?*

Whilst Parkinson's Australia has limited knowledge in relation to the operation of the LAC's any move to make the approval process simpler and more efficient would be welcomed. Moving the decision-making process closer to the client could be expected to result in more responsive planning and approval processes. However, the NDIA will need to ensure that LAC's have the skills, knowledge and experience to undertake plan approvals and there is some doubt that this is already in place.

It is recommended that given the implications to the participant that LAC's not be delegated the ability to decline approval and that this function only be undertaken by NDIA staff. In the case where an LAC is not able to approve a plan they should refer it through the appropriate NDIA channel for determination.

It is suggested that a continuous quality management approach be implemented where the NDIA would sample a small proportion of approved plans which would provide the ability to review, manage and improve LAC performance and manage any risks associated with devolved decision making.

## Draft Recommendation 4.1

*The National Disability Insurance Agency should:*

- *implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review*
- *review its protocols relating to how phone planning is used*
- *provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options*
- *ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants.*

Due to progressive nature of Parkinson's there is often the need to frequently adjust plans as the illness progresses, this is particularly important for some of the atypical Parkinson's conditions, such as Multiple System Atrophy, Progressive Supra Nuclear Palsy and Cortico Basal Degeneration, which can progress rapidly. Parkinson's Australia considers that facilitating minor amendments or adjustments to plans to reflect changes in a participant circumstances or changes in the service provision environment would remove unnecessary bureaucracy and assist in the smooth operation of the scheme. This role could be delegated to the LAC's provided they are trained appropriately.



One of the most common issues raised with Parkinson's Australia is the inadequacy of the phone planning approach. Speech difficulties and cognitive issues are common in Parkinson's and as such phone planning is totally inappropriate for people with these issues. For participants with complex progressive neurological conditions phone planning is generally considered to be a sub-optimal approach to providing support. Phone planning should be 'opt in' where a participant is given the option of using phone planning rather than it being the norm.

Many participants report that the planning process is confusing, difficult and frustrating. The provision of easy to digest information on how the process works, how and what a participant is expected to contribute during the process and what rights they have is essential to ensuring that quality plans are developed that meet the needs of the participant.

LAC's provide an important role providing education and connecting clients to services. It is essential that they be available before the scheme is rolled out to engage with potential participants and the local community. This early engagement should enable a smoother transition from current arrangements to the NDIS and assist in preparing potential participants for timely entry into the scheme in the most effective and efficient way.

#### Draft Recommendation 4.2

*The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.*

Planners often have little, if any, knowledge of progressive neurological conditions, such as Parkinson's, and that this directly impacts on their ability to develop plans that address the needs of participants. To offer true choice and control, NDIS planners must have knowledge of the condition, understand its disabling impact on participants so the unique needs of people living with Parkinson's can be addressed in individual plans.

It is strongly recommended that participants with progressive neurological condition, such as Parkinson's and atypical Parkinson's conditions, be managed by specialised planning teams that have a good knowledge and understanding of these conditions and the support and care that is required.

It has been reported to Parkinson's Australia that some planners have no relevant background in disability or health services. It should be mandatory that all planners have relevant qualifications and/or substantial experience in disability and/or health services and for those working with participants with progressive neurodegenerative conditions that they have additional knowledge about these conditions.

## Draft Finding 5.1

*It is a false economy to have too few resources for Information Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services.*

The NDIS is expected to meet the needs of around 475,000 Australians with a disability. This compares to almost 1 in 5 Australians, or 4.3 million people, with a disability, of which 2.1 million are of working age of whom 1 million are working or looking for work<sup>1</sup>. The disability sector is going to be required to provide additional supports well over and above that directly funded through the mainstream NDIS to ensure that people who are not eligible for the NDIS can remain as productive and supported members of the community.

It is essential that in an environment of very significant change in the disability sector that the majority of people who may not be eligible for the NDIS are able to link to, and receive, appropriate support services from mainstream services. This is particularly relevant for those who are in or seeking employment as it would be unfortunate if a scheme that has one of its objects to “support the independence and social and economic participation of people with disability”<sup>2</sup> actually resulted in people who are not eligible for the NDIS having reduced support resulting in greater social and economic disadvantage.

In its current form, and with limited funding, it is unlikely that the ILC will provide the support needed to ensure that mainstream services have the capacity to meet the support needs of people who are eligible or ineligible for the NDIS.

The ILC program should be reviewed, enhanced and accelerated to ensure that all Australians, not just those eligible for the NDIS, with a disability can link to appropriate services and support in their community. Consideration should be given to longer term contracts, funding for ongoing capacity particularly for services with a specialised knowledge of, and who support for people with, chronic conditions.

## Draft Recommendation 5.1

*Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount (of \$131 million) for each year during the transition. The funds that are required beyond the amounts already allocated to ILC to reach \$131 million should be made available from the National Disability Insurance Agency's program delivery budget.*

*The effectiveness of the ILC program in improving outcomes for people with*

---

<sup>1</sup> Australian Bureau of Statistics (ABS) 2016, 4430.0 - Survey of Disability, Ageing and Carers 2015.

<sup>2</sup> Clause 3, National Disability Insurance Scheme Act 2013

*disability and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed five-yearly review of scheme costs. The ILC budget should be maintained at a minimum of \$131 million per annum until results from this review are available.*

An accelerated and enhanced rollout of the Information, Linkages and Capacity Building Program (ILC), including an increase to the full ILC amount of \$131m, is strongly supported.

It is also recommended that the effectiveness of the ILC be evaluated well before the next COAG review of the scheme. This will ensure that any changes to the ILC, required to effectively support mainstream and other necessary disability services, are able to be implemented before that capacity of the sector is irretrievably reduced. This evaluation should be a part of a much broader evaluation on the impact of the NDIS on the wider disability, health and aged care sectors undertaken to determine whether there have been adverse and unintended consequences on these sectors because of the implementation of the NDIS and what impact this has had on the ability of Australians with a disability, particularly those not eligible for the NDIS, to receive the support they require to:

- maintain a good quality of life
- remain as independent and productive members of their communities.

#### Draft Recommendation 5.2

*The Australian, State and Territory Governments should make public their approach to providing continuity of support and the services they intend to provide to people (including the value of supports and number of people covered), beyond supports provided through the National Disability Insurance Scheme. These arrangements for services should be reflected in the upcoming bilateral agreements for the full scheme.*

*The National Disability Insurance Agency should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability.*

Concerns have been raised with Parkinson's Australia regarding continuity of services for people not eligible for the NDIS who are currently receiving disability services. The ongoing viability of services in an environment where funding that may have been available to support services has now been redirected to the NDIS is also of significant concern. It is essential that all levels of Government engage with the disability sector to ensure continuity of services for people not eligible for the NDIS and that information on the approach, including details of how services will be supported and funded, be publicly available.

It is essential that the impact of the NDIS on the disability services sector should be specifically and comprehensively addressed by the NDIA in its quarterly report. Given the potential impact and influence of the NDIA on the disability services market where it is likely

to be by far the largest purchaser of services the potential to have adverse or unintended consequences is significant and should be closely monitored.

#### Draft Finding 7.1

*It is unlikely that the disability care workforce will be sufficient to deliver the supports expected to be allocated by the National Disability Insurance Agency by 2020.*

Feedback and observations from the sector support this finding.

#### Draft Recommendation 7.1

*The roles and responsibilities of different parties to develop the National Disability Insurance Scheme workforce should be clarified and made public.*

- *State and Territory Governments should make use of their previous experience in administering disability care and support services to play a greater role in identifying workforce gaps and remedies tailored to their jurisdiction.*
- *The Australian Government should retain oversight of workforce development, including how tertiary education, immigration and aged care policy interact and affect the development of the workforce. In doing so, the Australian Government should pay particular attention to immigration policy to mitigate workforce shortages over the transition period.*
- *The National Disability Insurance Agency should provide State and Territory Governments with data held by the Agency to enable those jurisdictions to make effective workforce development policy.*
- *Providers of disability supports should have access to a clear and consistent mechanism to alert those tasked with market development about emerging and persistent workforce gaps.*

Whilst it is appropriate to identify the roles and responsibilities of the State, Territory and Federal Governments there needs to be a coordinated approach to disability workforce development and capacity.

Disability support and service organisations also have a role and the capacity to educate, support and develop the disability workforce. It is recommended that they be seen as a resource that can be used and supported by the NDIA and government to address workforce gaps.

#### Draft Recommendation 7.2

*The National Disability Insurance Agency should publish more detailed market position statements on an annual basis. These should include information on the number of participants, committed supports, existing providers and previous*

*actual expenditure by local government area.*

*The Australian Government should provide funding to the Australian Bureau of Statistics to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.*

Access to information on both NDIS participants, the broader disability service sector and disability workforce is essential and this recommendation is strongly supported.

#### Information Request 8.1

*Is support coordination being appropriately targeted to meet the aims for which it was designed?*

Support Coordination is a crucial service to people living with complex conditions such as Parkinson's which impact on all body systems, cognitive and affective issues are common and where the individual nature of the conditions and that every participant will be different. The Neurological Alliance of Australia has recommended the "Mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease"<sup>3</sup> Parkinson's Australia supports this recommendation.

#### Information Request 8.2

*Is there scope for Disability Support Organisations and private intermediaries to play a greater role in supporting participants? If so, how? How would their role compare to Local Area Coordinators and other support coordinators?*

*Are there any barriers to entry for intermediaries? Should intermediaries be able to provide supports when they also manage a participant's plan? Are there sufficient safeguards for the operation of intermediaries to protect participants?*

Disability support organisations, including specialised or condition specific organisations such as the State organisational members of Parkinson's Australia, have extensive and specialised knowledge about disabilities and health conditions that LACs and support coordinators would not generally have access to. Parkinson's is a complex and varied condition and it is unusual that services providers, who do not specialise in Parkinson's, have a good understanding of the range of symptoms and issues associated with it and how they impact on a person's ability to function.

Support Organisations are trusted and valued by the community and will often have strong relationships with their members that span many years and have a role in educating, informing and supporting. Support Organisations can:

---

<sup>3</sup> People with progressive neurodegenerative diseases in the NDIS. NAA Joint Position Statement available at <https://goo.gl/LPrd8Q>

- provide general education to providers, assessors and planners about particular conditions.
- offer education opportunities to participants and carers in relation to the management of their condition.
- inform participants about services that may support them.
- provide support, tailored to the condition, to participants through the process of applying to the NDIS and developing their plans.

The NDIS should recognise and support the role of support organisations that have specialised knowledge about specific conditions and disabilities.

#### Draft Recommendation 9.5

*In undertaking its role in delivering the National Disability Insurance Scheme, the National Disability Insurance Agency needs to find a better balance between participant intake, the quality of plans, participant outcomes and financial sustainability.*

As a part of the process of finding a better balance the NDIA should consider implementing a systematic approach to continuous quality improvement based on innovation, rapid-cycle testing in the field, and spread to identify and implement improvements in processes, quality and value. Such an approach would empower NDIA staff and contracted service providers to identify and address issues and to share learnings.

#### Information Request 9.1

*The Commission is seeking feedback on the most effective way to operationalise slowing down the rollout of the National Disability Insurance Scheme in the event it is required. Possible options include:*

- *prioritising potential participants with more urgent and complex needs*
- *delaying the transition in some areas*
- *an across-the-board slowdown in the rate that participants are added to the scheme.*

*The Commission is also seeking feedback on the implications of slowing down the rollout.*

Parkinson's Australia strongly opposes any move to delay or slow the rollout of the NDIS.

## Other Issues not identified in findings and recommendations

### Early Intervention

Parkinson's Australia believes that the Early Intervention Program provides an opportunity to support people living with Parkinson's to remain as productive members of the workforce and/or assist in ensuring that they can remain independent with minimal support services. Whilst in the early stages of Parkinson's it may not always be possible to easily demonstrate substantially reduced functional or psychosocial capacity, it is clear from the day of diagnosis that they are on a trajectory that will result in significant and permanent functional impairment. It has been shown that the provision of early support such as speech pathology, exercise physiology and psychosocial support services can reduce the impact of Parkinson's on a person's ability to function, particularly in the early stages of the condition, and allow them to remain in the workforce for longer and reduce complications associated with the condition.

### Impact on mainstream services

Anecdotal evidence suggests that as the NDIS is being rolled out that access to mainstream services for people not eligible for the NDIS is being adversely impacted. It has been suggested that support for mainstream services has been reduced as funding is transferred to the NDIS. This is of great concern as less than 20% of people with a disability will be eligible for the NDIS and they will continue to rely on support from the disability and health sector.

The NDIA, Federal, State and Territory Governments need to act now to ensure that capacity, skills and knowledge is not irretrievably lost with the sector.

### Boundaries between health and disability services.

There are often unclear boundaries between health and disability services. These boundaries are often interpreted differently by the NDIA and planners and can lead to participants being caught in a blame game where no one takes responsibility for services.

### Specialist Support and Information Services

The State member organisations of Parkinson's Australia provide specialist support and information services to people with Parkinson's, their carers and the health and disability workforce. These services are delivered through telephone and direct face to face counselling services, home visits and more than 300 support groups around Australia. These services are valuable to participants in helping them identify the types of services that they may need to include in their plans, they can also be a very valuable resource for NDIS planners in providing expert advice about conditions and their impact on participants. There appears to be no funding program within the NDIS that would support these services on an ongoing basis and, as such, these services are at risk.

There is anecdotal information emerging that some service providers are reducing or removing services in response to funding changes associated with the implementation of the NDIS resulting in those that are not eligible for the NDIS are losing access to valuable support services.

#### Low Utilization rates

It is unclear why the utilization rates are below that expected in the scheme estimates. Is there a gap between service demand and supply? Are plans making provision for services and support that are not really needed? Are there other issues with developing and implementing plans that are leading to lower utilisation rates?



## Background

### Parkinson's Australia

Parkinson's Australia is the national peak body and not-for-profit organisation representing more than 70,000 Australians living with Parkinson's and related conditions and 700,000 directly impacted by Parkinson's. Parkinson's Australia advocates for the needs of people living with Parkinson's, and for their families and carers.

Parkinson's Australia represents, at the national level, the interests of its federation of State and Territory members on all matters relating to Parkinson's and carer issues.

The role of Parkinson's Australia is to advocate on the basis of evidence-based policy, promote awareness of Parkinson's and administer national contracts with the Commonwealth Government.

Parkinson's Australia has a strong consumer focus and works with all Parkinson's State organisations who provide information, education, advice and support services to the Parkinson's community and support research into Parkinson's.

Parkinson's Australia is represented on the National Neurological Australia Alliance who advocates for better services to people affected by progressive degenerative neurological diseases in Australia.

### Parkinson's

Parkinson's is a progressive and substantially disabling neurodegenerative condition that affects people from all walks of life. Parkinson's is the most common major movement disorder and the second most common neurological degenerative condition, after dementia. It is conservatively estimated that 70,000 Australians are living with Parkinson's with approximately 32 new cases of Parkinson's diagnosed every day. Approximately 1,743 people die from Parkinson's every year.

Whilst 'typical' or idiopathic Parkinson's constitute the vast majority of our community there are a number of 'atypical' Parkinson's conditions including Multiple System Atrophy, Progressive Supra Nuclear Palsy, Lewy Body Dementia and Cortico Basal Degeneration which have signs and symptoms similar to Parkinson's. People diagnosed with an atypical Parkinson's condition are generally younger, will need a more rapid response due to the aggressive nature of the conditions and have a poorer prognosis than those with Parkinson's.

The average age of diagnosis is 65 years and 82% of people living with Parkinson's are over the age of 65. However, people as young as 20 years can be diagnosed with Parkinson's and this is referred to as Young Onset Parkinson's.

According to ABS data in 2012 there were 3,061 deaths where Parkinson's was an associated cause, of these in 46% Parkinson's was the underlying cause.

Parkinson's is not easy to diagnose. There are no laboratory tests (such as a blood test or brain scan). The diagnosis is made on the basis of the clinical presentation and history of the patient so it is important that the diagnosis is made by a specialist, such as a neurologist.

Parkinson's is characterised by a wide variety of signs and symptoms that affect both motor and non-motor areas of the brain which impact on all body systems. Parkinson's symptoms are mostly attributed to the reduction in a key neurotransmitter production (dopamine) in the brain. The reduction in dopamine causes difficulties in the coordination of muscle movements and contributes to mood and cognitive disturbances in the later stages of the condition.

Typically, the signs and symptoms include:

- Bradykinesia and Akinesia (slowness and absence of movement)
- Muscle Rigidity (freezing)
- Tremor
- Postural Instability
- Fatigue
- Speech and swallowing difficulties
- Mood changes including anxiety and depression
- Sleep disturbances/changes
- Gastrointestinal symptoms including slowed gastric emptying and constipation
- Issues with regulation of body temperature and blood pressure
- Sensory changes including loss of smell and changes to vision
- Significant cognitive changes including hallucinations, memory loss and dementia particularly in the later stages of the condition

Parkinson's is a progressive condition but with significant variation between individuals. Each person living with Parkinson's will experience a different journey and may not experience all symptoms.