



Submission to the Stage 2
consultation on the proposed new
National Disability Strategy

October 2020



Our Vision

Promote the best possible quality of life for people with Parkinson's.

Our Purpose

We advocate for the Parkinson's community on issues of national significance. We work to reduce the impact of Parkinson's by promoting best practice care to ensure that people can maximise their opportunities to live well and maintain their independence.

Our contact details

Parkinson's Australia Inc

Unit 4, 25 Manuka Circle
Forrest ACT 2600

PO Box 108
Deakin West ACT 2600

☐ ceo@parkinsons.org.au

Introduction

Parkinson's Australia welcomes the opportunity to make a submission to the NDIA about the next stage of the National Disability Strategy.

Drawing on the experiences of the Parkinson's community, this paper responds to the questions set out in the NDS Position Paper.

It is important to build on the achievements of the previous Strategy, while at the same time responding to areas of unmet need identified by people living with disability. Listening to the voices of people with a disability is critical in the development of a disability sector that provides optimal support to the people in it.

The proposed amendments to be included in the revised Strategy must ensure that services in the sector are characterised by accessibility, accountability, clarity and inclusivity. It must reflect the views of non-government agencies and advocacy groups in the disability sector, as well as those of people directly affected. Working together, in cooperation, is needed to provide the most effective and equitable pathway for improving people's wellbeing. Additionally, transparency at all stages of implementing the Strategy will work to break down misinformation and provide greater assurance that people's wellbeing is the primary focus of the NDIA and DSS.

Question 1:

During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

In regards to the change from 'citizen' to 'members of the community', Parkinson's Australia believes that this change will result in a dual understanding of Australian society. 'Citizen' promotes equality between all people of Australia (no distinction between those with disability and those without); however, 'members of the community' separates people with disability into their own separate community. This distinction is in violation of the *United Nations Convention on the Rights of People with Disabilities*, as well as the purpose of inclusivity (an outcome and guiding principle identified in the former and proposed NDS). For this reason, it is proposed that 'citizen' be retained.

As identified in the Independent Review on the implementation of the *National Disability Strategy 2010-2020*, it is essential that, in effecting changes at a system, state or territory level, disability community groups and individuals are closely involved with the design. It is essential that there is a targeted approach to addressing the needs of people with disability, carers and health care professionals. A general, overall approach may provide a governance Strategy; however, support (the most essential objective of the Strategy) must be tailored. As evidenced in the *Right to opportunity | Consultation report to help shape the next national disability Strategy 2019*, the complicated and unclear procedure for accessing NDIS has had the effect of limiting access to the NDIS and aged care support.

During the period 2010-2020, there has been an increase in the number of people with Parkinson's, and this growth is expected to continue. However, there has not been an effective response by the NDIA to serve the Parkinson's Community. Community feedback has suggested greater support at all stages of Parkinson's is essential; especially for people with Young Onset Parkinson's, who are often ineligible for NDIS and Aged Care. This makes them a particularly vulnerable subgroup whose circumstance should be recognised and catered for in the new Strategy. Furthermore, a lack of home

care packages for people with Parkinson's (an issue also identified in the Royal Commission into Aged Care and Safety) represents another failure of the current Strategy.

Moreover, and importantly, the majority of respondents to the 'Right to Opportunity' report (83 per cent) noted that awareness and understanding of disability had not improved under the current NDS and outcomes. This deficiency underpins all other outcomes and has a significant impact upon the success of any Strategy. The revised Strategy must include a focus on this matter and how it can be improved.

Question 2:

What do you think about the guiding principles proposed here?

The proposed guiding principles are important and reflect much needed and identifiable action to support people with disability. However, a key aspect not proposed is accessibility.

For example, Parkinson's Australia believes that access to the NDIS would be much improved if the information provided and the steps to be taken were described in plainer language.

Many within the Parkinson's community have struggled with the maze of complicated actions needed when seeking support. Furthermore, the complicated language and requirements for form-filling and information-gathering have been significant impediments to many; often requiring outside assistance. This is concerning given independence is a primary outcome and, indeed, a declared right (according to the *United Nations Convention on the Rights of Persons with Disabilities*).

Question 3:

What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

Changing community attitudes is very important; but no more so than changing the attitudes of governments, service providers and the general public. To participate fully in society, people with disability should not be subject to stigma or any other negative attitudes. The revised Strategy should include references to how attitudinal change and empathy can best be achieved.

We have heard from a number of people with Parkinson's about the stigmatisation of the condition in the general community and particularly in the workplace. Many try to hide having Parkinson's out of fear of being stigmatised or overlooked in work. For many, misinformation about Parkinson's, particularly in the general population, remains significant. There is quite common uncertainty about who Parkinson's affects, the symptoms experienced, and the likely trajectory of the condition. Many people have reflected on the difficulty of dealing with NDIS and Aged Care staff who do not understand Parkinson's, who cannot empathise with a person's condition and cannot provide sound information or support. Clearly a stronger emphasis and action is needed to change community attitudes.

While attitudinal change is important (and can be facilitated via close and open relationships between governments, non-government organisations and individuals) key support areas, such as primary health services, are a primary concern for many living with Parkinson's.

Question 4:

How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

Clarity is essential at all stages of support, and is especially important for disability support. The responsibilities of every stakeholder engaged in support must be clear, easily understandable and their responsibilities clearly communicated.

We have heard from the Parkinson's community the need for greater clarity as they engage with various support options. Parkinson's is a neurodegenerative condition, and as a result, the person's needs will change over time. This inevitably will require the individual to interact with a multitude of services providers and supports, and the content and nature of these interactions will need to change as the person's condition changes. Service providers need to understand that what was right for the individual at one point in time, may not be right now.

There must be a clear framework and set of processes put in place, as well as support mechanisms to streamline transitions between levels of government, non-government agencies and support groups. At the moment, many have reflected on the difficulty in transitioning between service providers (there is little to no communication between levels).

Furthermore, governments at all levels must acknowledge this importance and provide support for disability support groups, as they are a primary source of information and care for people with disability. Governments should work with particular disability sectors and support services to ensure that information and support is available where and when people with disability need them.

Question 5:

How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability?

Non-government agencies are often in the front line in supporting people with disability, providing information, assisting wellbeing groups and advocating on their behalf. These groups often provide necessary support groups and important community insights, as well as advocacy pathways for people to get their voices heard within the community. In systems where lodging grievances or seeking information is complex, these groups have a particularly important voice in representing community groups. Among other things, they can, in partnership with other NGOs and community groups, advocate to governments for change. However, the Strategy must first start with a government-led approach, whilst supporting and funding non-government groups. To this extent, strategizing initiatives into disability research, support and wellbeing must start at the government level and work with non-government groups, rather than it being necessary for non-government groups to initiate some of the support mechanisms or research for each condition.

Non-government agencies involved with people with a disability vary considerably in their size and their ability to raise funds and, therefore, in their capacity to provide support for their target group. As a result, some sub-groups in the disability sector have significantly more support than others. The government has a role to play to ensure a basic minimum amount of support can be provided by non-government agencies.

Question 6:

What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

Clarity is, again, essential. Standards must be put in place to adequately assess the success of disability support. Moreover, standards for those working in disability support must also be clarified and made uniform. Setting certain outcomes, indicators and measures is essential for articulating the areas of success (and how success can be continued) and of continuing concern (and how these can be overcome). However, the key point of these benchmarks is to respond to them and, in consultation with consumers and non-government groups, articulate exactly how response will be made. Access to information is, currently, a very difficult and time-consuming task, which is problematic for many people with disability, including for people with Parkinson's who suffer from fatigue.

To ensure the accessibility of information, it is important to display results regularly and in a manner consistent with the needs of the diverse community. To ensure this, and accountability, an external and independent group should be set-up. Information on activities, outputs and outcomes should be reported annually to ensure standards are being met and, as necessary, actively addressed.

Question 7:

What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years)?

We support the idea of a targeted action plan. By separating overall outcome into clearly defined and manageable sections, organisations can prioritise and better integrate government support into these time Action Plans. Moreover, competition between the various disability support groups could be better managed this way and the outcomes for all people with disability could be improved. However, the issues of who determines the priorities and how these are determined/enforced will need to be addressed to gain full support from the community.

Governments, non-government and non-for-profit organisations must work together to set and achieve these manageable outcomes.

Question 8:

How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in the delivery and monitoring of the next Strategy?

Active participation is very important; however, this Strategy remains unclarified as yet. For example, the need for plain language, clarity in the purpose of the Strategy and its outcomes for key areas, including; housing, employment, income support, health and education, is necessary so that everyone knows, understands and engages with the Strategy. The need to clarify how people with disability – and carers and family members – can be actively involved in the enhancement of the Plan needs refinement. For example, employment is one area, yet there are many other areas people living with disability are involved in. Accordingly, regular community consultation (including actively engaging non-government organisations that represent disability groups) is essential to achieve greater representation of the community voice and provide feedback to the governments. However, governments should frequently engage people with disability through consumer feedback spaces, and regularly publish successes and grievances.

Engagement strategies cannot, however, be universal. As Australia's community is diverse, so too must be the response to each disability be understood and represented.

Question 9:

Is there anything else you would like to share about the ideas and proposals in the position paper?

The revised Strategy must be premised on a holistic approach to care for those in the disability sector, with a primary focus on accessibility of services. This means that the systems must be as simple as possible and made available to those they serve using straightforward, culturally appropriate language. The holistic nature of the disability services sector will mean that all aspects of disability support and care are covered including, in particular, those relating to employment, education and health. There needs to be effective communication between the clients themselves, their carers, the managers and providers of the clinical/technical services, and the bureaucracy responsible for management in the sector. The Strategy must comprehend and allow for the key role played by support groups working with particular forms of disability. The revised Strategy must also look outward to the broader Australian community and provide the means to ensure that those with a disability and their sector as a whole are understood, supported and appreciated.

Conclusion

Thank you for the opportunity to provide feedback on the proposed new Strategy as part of the Stage 2 Consultation Process. We look forward to the outcomes of this consultation stage and the development of a holistic and responsive Strategy for people living with disability, and in particular people with Parkinson's.