1 July 2021

Two new reports are available about participants with a sensory disability in the NDIS and participants with neurodegenerative conditions in the NDIS.

These reports provide detailed information about the experiences of these groups of participants to help the NDIA, sector, providers and other interested people to understand how to work best with these participants to achieve their goals.

The report on sensory disability is about NDIS participants with hearing, visual, or other sensory/speech impairments.

The report on neurodegenerative conditions is about NDIS participants with the following five conditions: Muscular dystrophy, Huntington's disease, Motor neurone disease, Multiple sclerosis, and Parkinson's disease.

Both reports are divided into four sections and cover: participant characteristics, participant experience of the NDIS, plan supports and payments for supports, as well as participant goals, outcomes and satisfaction.

Working with NDIS participants to understand and measure their experiences with the Scheme, as well as the progress they are making with their plan goals, is an important part of our work.

The NDIA regularly releases data about the Scheme on the NDIS Data and Insight website where you can explore and customise NDIS data of interest to you.

Releasing data to the public is part of our commitment in the NDIS Participant Service Charter to be transparent.

Key findings - sensory disability

At 31 March 2021, there were 449,998 active NDIS participants with an approved plan. Of these 33,500 had a primary sensory disability:

- 21,700 (4.8%) had a primary disability of hearing impairment
- 8,897 (2.0%) had a primary disability of visual impairment
- 2,903 (0.6%) had a primary disability of other sensory/speech impairment.

Participants set goals as part of the NDIS planning process.

Participants with hearing, visual, and other sensory/speech impairments most often set goals related to daily life, social and community activities, learning, and health and wellbeing.

Key findings – neurodegenerative conditions

At 31 March 2021, there were 449,998 active NDIS participants with an approved plan. Of these 14,389 had a neurodegenerative condition:

- 2,258 (0.5%) had Muscular dystrophy
- 945 (0.2%) had Huntington's disease
- 789 (0.2%) had Motor neurone disease
- 8,263 (1.8%) had Multiple sclerosis
- 2,134 (0.5%) had Parkinson's disease.

Participants set goals as part of their NDIS planning process.

We are seeing participants with a neurodegenerative condition most often set goals related to daily life, social and community activities, and health and wellbeing.

You can read these participant reports and others in more detail.

Related articles

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- Neurodegenerative, Palliative Care and Rare Diseases Advisory Group communique

Neurodegenerative, Palliative Care and Rare Diseases Advisory Group Meeting January 2025

Date
29 January 2025
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- Neurodegenerative, Palliative Care and Rare Diseases Advisory Group communique

Neurodegenerative, Palliative Care and Rare Diseases Advisory Group meeting September 2025

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