

Carers Missing Out

FACT SHEET

This is a summary of a report commissioned by the NSW Carers Advisory Council.¹

Its aim was to establish if **carers of people with disability under 65 years** are **missing out** on support since the introduction of the National Disability Insurance Scheme (NDIS), and if so, who is missing out, why are they missing out and what can be done about it. Carers are the unpaid family and friends who provide ongoing essential care.

Most carer support services funded in NSW ceased with the introduction of the NDIS. Funding for the Commonwealth funded National Respite for Carers Program (NRCP) also ceased.

Only limited replacement services are available through the new Commonwealth Carer Gateway.

The report focuses on three groups:

- Carers of people with a mild to moderate disability.
- Carers of people with chronic illness resulting in disability, particularly those with cystic fibrosis or multiple sclerosis.
- Carers of people living with mental health issues (particularly those whose issues are mild to moderate or episodic).

Key Findings and Proposals

- Around 60,000 **primary carers** of people with disability in NSW **need more support**.
- **74% of people with a disability** in NSW who need assistance to perform daily activities **do not have access to an NDIS package**.



Number of Active NDIS participants in NSW compared to ABS estimates of people aged 0-64 years with disability needing assistance (Dec 2019).

- **More than 120,000 people with disability** in NSW report a need for **more formal assistance**. This has a major impact on carers.
- People with a disability across the three focus groups are often assessed as ineligible for the

NDIS despite being 'eligible' according to the NDIS Act. For example, **less than 13 percent** of people with cystic fibrosis who have severe functional limitations **get the help they need**.

- To ensure that participants' needs are met, carers' needs are met and NDIS plans are efficient and sustainable, **it is essential that carers be involved** in NDIS assessment processes.
- **Carers need to be recognised** in relation to their own needs, circumstances, skills, and strengths, regardless of the NDIS eligibility of those for whom they care.
- **Development of effective referral processes between the NDIS, the Carer Gateway and mainstream support services is essential**. Adequacy and appropriateness of Carer Gateway services must be adjusted in response to carer needs.
- **Additional services are needed in NSW to address the needs of carers and people with disability who remain outside the NDIS**.

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