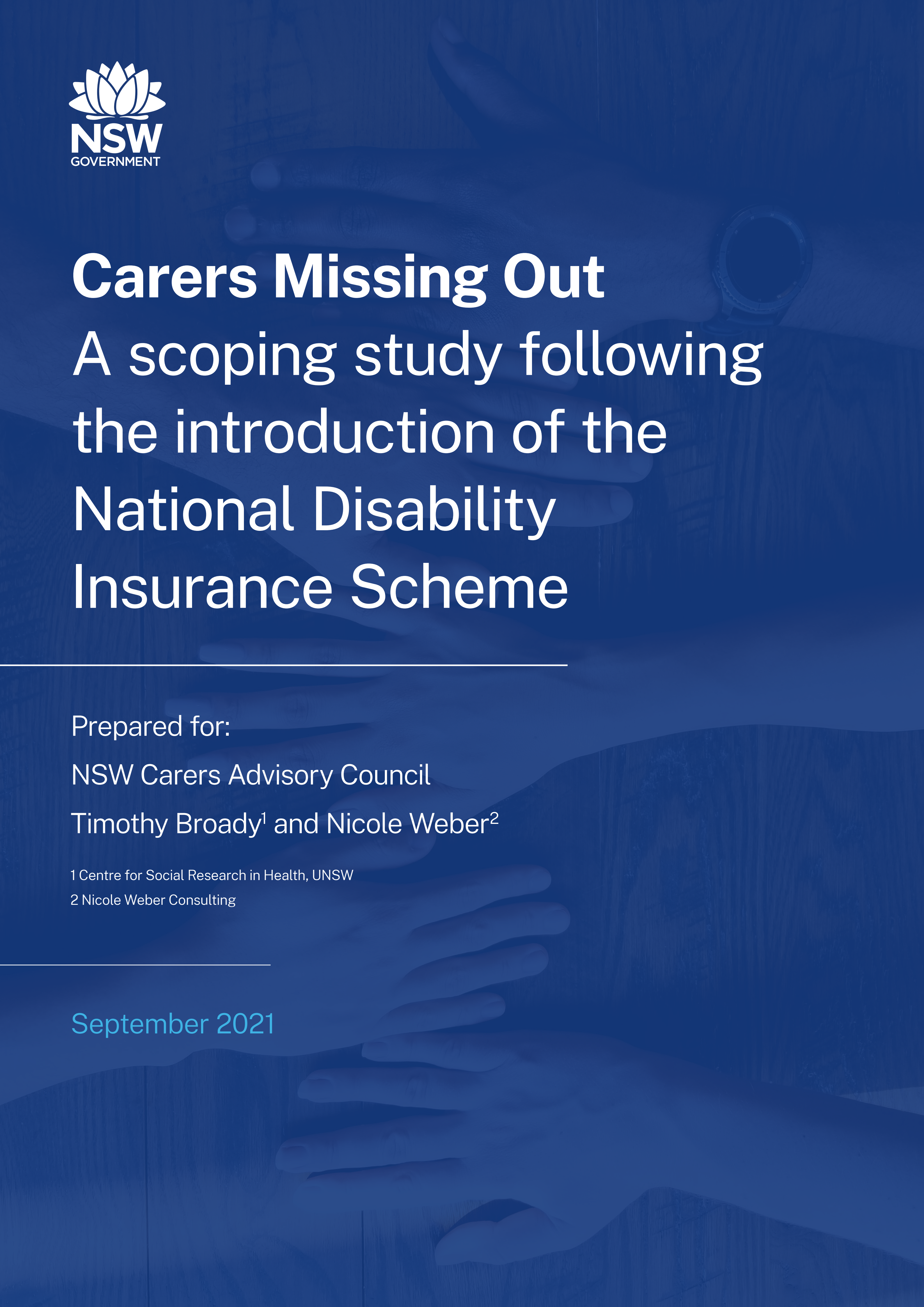

# Carers Missing Out

## A scoping study following the introduction of the National Disability Insurance Scheme

Prepared for:

NSW Carers Advisory Council

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# Contents

# Executive Summary

This report was commissioned by the NSW Carers Advisory Council to examine whether there is evidence to support claims that carers in the state are missing out on essential services to support their responsibilities caring for a family member, partner or friend, following the introduction of the National Disability Insurance Scheme (NDIS).

The report aims to:

- establish whether there is strong evidence that carers of people with disability in NSW are missing out on the support they require since the introduction of the NDIS, and if so, why they are missing out
- identify in broad terms which carers are missing out
- identify broad options for meeting the needs of these carers.

Therefore, the project has a specific focus on those situations where carers are missing out on necessary support. The research undertakes a more in-depth focus on three particular groups of carers:

- carers of people with a mild to moderate disability
- carers of people with chronic illness resulting in disability
- carers of people living with mental health issues (particularly those with mild to moderate or episodic disability).

## Background

Reforms to disability policy and service provision involving individualised support for people living with disability have had significant impacts on carers. These reforms were implemented with the introduction of the *National Disability Insurance Scheme* (NDIS) in July 2016 and were intended to replace the existing disability service system for people under the age of 65 with a person-centred system, giving people with disability far greater control over the services they receive.

The introduction of the NDIS has had positive outcomes for many people with disability and their carers, including increased levels and quality of services. The NDIS is, however, a highly targeted (rationed) scheme. Data from the NDIS and Australian Bureau of Statistics (ABS) presented below indicate that in December 2019 only 26.5% of people with disability in NSW who need assistance to perform daily activities were receiving an NDIS package. Some of the remaining 73.5% who were not accessing an NDIS package may have received formal support through other service systems (e.g., health, education, transport), however, it is also likely that family and friends provide substantial support to these individuals.

### Table 1 Number of active NDIS participants in NSW compared to ABS population estimates of people aged 0–64 years with disability needing assistance (Dec 2019)

| | Needs Assistance[1] | | | Active NDIS Participants[2] | Percentage accessing NDIS package[3] |
|---|---|---|---|---|---|
| | Mild/Moderate Limitation | Severe/Profound Limitation | All | | |
| Age | | | | | |
| **0–14 years** | 11,400 | 61,600 | 80,300 | 45,491 | 56.7% |
| **15–24 years** | 18,900 | 33,100 | 62,100 | 19,320 | 31.1% |
| **25–64 years** | 128,600 | 124,400 | 285,800 | 45,193 | 15.8% |
| Location | | | | | |
| **Sydney** | 80,900 | 127,400 | 240,400 | 49,749 | 20.7% |
| **Rest of NSW** | 79,400 | 89,400 | 186,900 | 63,825 | 34.1% |
| **Total** | **160,300** | **217,500** | **429,000** | **113,590** | **26.5%** |

Note: Numbers in this table do not add up to row and column totals due to missing data and standard error of population estimates generated by TableBuilder.

1 Needs assistance or has difficulty with broad activity area. Source: ABS (2018a)

2 Source: NDIS participant data, December 2019

3 Percentages reflect the number of active NDIS participants as a percentage of total number of people with disability needing assistance.

## What has changed?

When the NDIS was established, responsibility for management of its predecessors, the *Home and Community Care Program* (HACC), and later the *Community Care Support Program* (CCSP), as well as funding for specialist disability support services was transferred from NSW to the Commonwealth[i]. In addition, funding for the Commonwealth funded National Respite for Carers Program (NRCP) ceased. These and other major changes have had a negative, if unintended, impact on many affected carers.

Prior to the transfer, carers could access supports in their own right, as part of the assistance provided by HACC, the NRCP, the Support Coordination Program for Older Parent Carers, and specialist disability services. Key supports through these programs included domestic assistance, social support, case management and respite. Carers were routinely consulted, at the point of assessment, about the support needs of the person for whom they cared. Carers could access basic information and help in navigating the service system from NSW service providers. In addition, a range of disability support services provided in NSW under the previous funding arrangements were no longer available. Some continue, but access is restricted to approved participants of the NDIS. This has had a significant impact on those carers who struggle to directly fill and/or fund the service gaps.

Since the transfer of disability support programs to the Commonwealth, direct support for carers of people aged 0–64[ii] can be accessed through the recently established Commonwealth Carer Gateway. This now operates as the primary mechanism through which carers can access support services to meet their own needs. The Gateway offers services such as counselling, online peer support, online coaching and educational resources to all carers based on assessed need. However, it does not ensure they have a right to discuss the support needs of the person for whom they care with the NDIS or other service agencies. It offers carers more limited access to personal support than was previously available to them in NSW. For example, services such as domestic assistance and respite may now be accessed through a limited number of packages valued at up to $3,000 per annum. Sector experts consulted in this scoping study advised that these packages are inadequate to provide sustainable support to carers, unlike the services previously available.

## Research Approach for the Scoping Study

Using existing data from the ABS and the NDIS, this report estimates the number of people with disability and carers missing out on essential supports. Other reliable survey data has also been used to shed light on carers' access to services and support.

To explore the impact of the restructuring of disability support on service provision, individual carers and their families, interviews were also undertaken with 15 sector experts and 10 service providers. Six carer case studies were also conducted. It was not possible to interview a large representative sample of carers for this study, therefore these case studies do not necessarily reflect the overall impacts of the NDIS for all carers in NSW. However, in keeping with the focus of this project, these interviews illustrate some significant outcomes of the move to the NDIS and the abolition of the pre-existing state-funded system of support services on those carers who have missed out on support as a result.

### Summary of Findings

**Carers of people who need help but are not eligible for the NDIS**

The ABS and NDIS data analysed for this study (see Table 1 above and Section 2 for more details) show that in December 2019, 26.5 percent of the disability population in NSW needing assistance with core tasks received an NDIS package. That is, approximately three out of every four people with disability in NSW do not receive an NDIS package. Some of these individuals may access supports through other service systems (e.g., health, education), however, a substantial population of people with disability report needing additional assistance (as outlined in the following paragraphs). This has a major impact on their carers who have continued to be responsible for providing ongoing care and support, but now lack the support of former state-funded services which until recently helped them share their load.

> When a person with disability is deemed ineligible for the NDIS, there are often significant consequences for carers, as a number of the case studies presented in this report demonstrate.

In total, 121,600 people with disability aged 0–64 years in NSW received informal assistance from family and friends, but needed more formal, funded support from the NDIS or another formal service. Their carers, who include over 59,000 primary carers, also missed out on support. The largest numbers of these were those caring for people with a severe to profound disability. A disproportionately high proportion of those caring for people with mild to moderate disability also need more support.

When a person with disability is deemed ineligible for the NDIS, there are often significant consequences for carers, as a number of the case studies presented in this report demonstrate. More attention is required to address the support needs of people with disability and their carers outside the NDIS. It is important that effective referral pathways are established between general purpose or mainstream support services, the NDIS, and the Carer Gateway.

### Carers of those eligible according to the *NDIS Act* but deemed ineligible by service planners (assessors)

Several common issues were raised across the three groups of carers that are the subject of the more in-depth focus of this project; carers of people with a mild to moderate disability, carers of people with chronic illness resulting in disability, and carers of people living with mental health issues. Carers and service providers interviewed reported that members of each of the three groups are likely to experience the very real possibility that despite being ‘eligible’ according to the *NDIS Act*, those for whom they care will be deemed ineligible for a funded package. The carers of people with chronic health conditions and those of people living with mental health issues appear to be particularly at risk.

Further, it became increasingly evident in the study that many who believe they are eligible are deemed ineligible after their application has been assessed. There is a need for Local Area Coordinators (LACs) and NDIS planners who are responsible for assessing eligibility to develop a much clearer understanding of the episodic nature that characterises many disabilities, especially those resulting from chronic illness or those living with mental health issues. Similarly, planners' understanding of the functional limitations resulting from disability needs to be enhanced, so that people with severe functional limitations are not erroneously deemed ineligible due to the focus on medical diagnosis. This was of particular concern for people with serious chronic illness (as exemplified in the case studies concerning cystic fibrosis) that can result in severe functional limitations.

## Carers of those who use the NDIS

The importance of involving carers of people who currently receive support through the NDIS, and those who seek support for their loved one or friend also needs to be stressed. Listening to carers should not be seen as conflicting with ensuring that people with disability who need assistance have a right to express their own views, make their own choices and take control of their own lives wherever possible. In particular, some people with mild to moderate disability and people living with mental health issues may not want to access support services, may lack the capability to explain their need for support, or may lack the insight that they already depend on the support provided by unpaid carers and family members. If carers are not involved in the application process to provide necessary information or act in an advocacy role, these individuals and their carers may miss out on necessary support.

Supporting carers of all people with disability is essential to the effectiveness of the NDIS. This is particularly evident within the three target groups of this project, as the evidence discussed in Section 4 of this report demonstrates. As well as ensuring that all people with disability receive necessary supports, it is imperative that carers are supported on the basis of their own needs as well as acknowledged as keystones in the support relationships of those for whom they care. Failure to address these gaps in the disability support system risks the unnecessary breakdown of large numbers of informal care relationships at great financial and social cost to the community and care recipients, as well as to the carers involved.

# Key takeaways from the scoping study

## Who is missing out?

1. The data presented in this report estimates that around 60,000 primary carers of people with disability in NSW need more support. Stakeholder consultations suggest that support available to carers has declined significantly since the introduction of the NDIS.
2. Approximately 74% of people with disability who need assistance to perform daily activities in NSW do not have access to an NDIS package and therefore rely on other service systems, and in particular on family and friends.
3. More than 120,000 people with disability in NSW report a need for more formal assistance. This has a significant impact on their carers.

## Agenda for Change

### Equitable Access to the NDIS and Other Support Services

4. There is a need for clear guidance for assessors regarding the consistent application of NDIS eligibility criteria. Guidance must include a focus on the functional limitations resulting from disability, to ensure that people are not erroneously excluded from the scheme. This is of particular concern for people with serious chronic illness (such as cystic fibrosis) that can result in severe functional limitations.
5. There is a need for a clear understanding of the episodic nature that characterises many disabilities (including those resulting from chronic illness or those living with mental health issues) to ensure that such people are not excluded from accessing the NDIS.

### Recognising the Voice of Carers and Enhancing Support

6. Involving carers in NDIS assessment processes is essential to ensure that participants' and carers' needs are met, and NDIS plans are efficient and sustainable.
7. 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.
8. Developing effective referral processes between the NDIS and mainstream support services to the Carer Gateway must be a high priority for health and other service providers. The adequacy and appropriateness of the services available through the Carer Gateway should also be closely monitored and adjusted in response to carer needs to ensure that carers are not missing out on essential supports.

9. Policy and service system planning is needed in NSW to address the needs of carers and people with disability who remain outside the NDIS. The NSW Carers Advisory Council notes the data presented in this report provides a clear case to consider the reinstatement of readily accessible basic information, advice and peer support services for carers as a form of cost-effective primary care together with good access to planned respite care. The sorts of assistance such services could provide includes:

- participatory carer social support groups, in which carers share experiences and develop forms of mutual assistance
- information and referral services (in-person and by telephone) that would complement the online resources currently available through the Carers Gateway
- access to some forms of direct assistance, such as advice on home adaptation and modification, help with transport, shopping, domestic assistance, home maintenance, in home respite, access to day care and other advice and support services at home and in the community
- basic research and advocacy functions, in which common problems can be identified and remedial response plans developed.

While the introduction of the NDIS has resulted in positive outcomes for many people with disability and their carers, the results of this scoping study highlight situations where this is not the case. The evidence demonstrates a pressing need for effective strategies and initiatives to address these issues.

# 1. Introduction

## Case study – Graham

Graham, aged in his early 60s, is the primary carer for his son, Luke, who recently turned 30. Graham has been Luke's carer since his son was a teenager. Luke lives with autism and dyspraxia, and experiences extreme social phobia.

Graham provides practical and emotional support to Luke on a daily basis. Luke can take care of some basic cooking and cleaning and ordering groceries online. Graham helps Luke plan healthy meals, prompts him to shower, and takes him to appointments. Luke will not leave the house without Graham because of his social anxiety. Graham worries that Luke is socially isolated. He has a small group of friends that he connects with online, but none in his local area.

Graham is apprehensive about what will happen in the future. Graham would like to see his son living independently, but Luke would need funded supports for that to happen (e.g., support with social interactions, shopping, study, and maintaining routines).

Graham says he finds it challenging that the NDIS terminology does not recognise the role of a carer but instead talks about a 'nominee'. Luke has not yet submitted an access request to be considered for the NDIS and his mental health affects his ability to do so. As such, there is no support for Luke other than what Graham provides. Graham never gets to 'switch off'. He says, 'It's not how I imagined life would be with a 30-year-old son.'

Reforms to disability policy and service provision involving individualised support for people living with disability have had significant impacts on family carers like Graham. These reforms were implemented with the introduction of the National Disability Insurance Scheme (NDIS) in July 2016 and were intended to replace the existing disability service system for people under the age of 65 with an expanded, more consistent, accessible, and person-centred system.

Under the NDIS legislation, carers are not participants in the NDIS themselves (Cresswell, 2017), which has important implications for their ability to access services. Their lack of recognition in the NDIS persists despite the Productivity Commission's recommendation that where carers 'meet a large share of a person's support needs, they would receive their own assessment to establish [the] sustainability of that care and ways in which they could be supported' (Productivity Commission, 2011, p18).

## 1.1 Aims and objectives of this scoping study

In responding to the changes in policy and service provision outlined above, this scoping project was developed to:

- establish whether there is strong evidence that carers of people with disability in NSW are missing out on support they require since the introduction of the NDIS, nd if so, why they are missing out
- identify in broad terms which carers are affected
- identify broad options for meeting the needs of these carers.

The research undertakes a more in-depth focus on three particular groups of carers:

- carers of people with a mild to moderate disability
- carers of people with chronic illness resulting in disability
- carers of people living with mental health issues (particularly those with mild to moderate or episodic disability).

## Background

Carers have navigated several major changes since the NDIS was introduced. One notable example relates to direct services for carers. As stated by one sector expert interviewed as part of this study, ‘Mainstream supports for carers no longer exist.’ As discussed below, many of the services previously available are no longer funded to provide support and have consequently either ceased operation or been restructured to continue under the new NDIS provisions, without providing support for carers. While the Carer Gateway, a new specialist program designed to help individual carers, has recently been introduced by the Commonwealth, it does not provide support for the people that carers assist.

> ‘Mainstream supports for carers no longer exist.’

## 1.2 Support for carers before the NDIS

With the introduction of the NDIS, there have been significant changes to support for carers and people with disability. These changes reflect major shifts in state and national policy approaches to disability and carer support, in particular:

1. The transfer of the Home and Community Care Program (HACC) to the Commonwealth, where it has since been redesignated as:
    a. the *Commonwealth Home Support Programme* (CHSP), focusing as the entry tier of aged care for people over 65 years of age
    b. the *Community Care Supports Program* (CCSP) to provide HACC-type supports to people with disability under 65 years of age, who are eligible for the NDIS
3. The transfer of responsibility for other major disability service funding from NSW to the NDIS
4. The closure of most carer support services previously funded by the NSW programs and the cessation of carer support activities provided by disability support services and other agencies,[iii] including 16 Commonwealth CareLink and Carer Respite Centres (CRCs) that operated in NSW. CareLink and the CRCs were the primary mechanism for carers to access services. With the transfer of responsibility to the Commonwealth some but not all, of their remaining functions have been taken on by the Carer Gateway.

Prior to the NDIS, the HACC program, which had both the person with a disability and the carer as the target group, and the *National Respite for Carers Program* had flexible guidelines that enabled organisations to support a range of carers and caring situations. The HACC program in NSW allowed carers to access domestic assistance, social support, and respite. Although the program has been discontinued in NSW, similar programs funded by other state governments have continued to provide disability support outside of the NDIS (e.g., the *Victorian HACC Program for Younger People*: DHHS Victoria, 2020). To date, no formal assessment has been undertaken to assess the impact of the discontinuation of these HACC and respite services on carers in NSW or elsewhere in Australia. Joint Commonwealth/state funding was also provided under the *Respite for Ageing Parent Carers Program* through the 2006 bilateral agreement and continued until the implementation of the NDIS.

The *Support Coordination Program for Older Parent Carers* is another state-funded carer support program that ceased operation following the establishment of the NDIS. It offered a case management service specifically designed for carers beyond the care needs of the person for whom they were caring. While the system was flawed (Productivity Commission, 2011), one benefit was that carers could discuss the care and access support they believed their family member required, such as respite, advice, information, or membership of a carer support group, in their own right.

Both the Commonwealth and NSW governments stated that no one would be worse off under the NDIS:

> ‘No one will be disadvantaged in the move to the NDIS. People who had been receiving specialist disability support, but are not eligible for the NDIS, will maintain the same outcomes they received before the NDIS.’
>
> (NSW Government Fact Sheet -
> *Eligibility Requirements for the National Disability Insurance Scheme Fact Sheet, 2016)*

This information was passed on to carers of all people in NSW receiving an ADHC (Ageing Disability Home Care) funded disability service.

## 1.3 Carers missing out after the introduction of the NDIS in NSW.

The national rollout of the NDIS commenced in July 2016, with all NSW funded disability services (and associated funding) transferred to the NDIS by July 2018. This meant that services previously provided in NSW were no longer available to people unless they were an approved participant of the NDIS.

In NSW, approximately 79,000 people were expected to transfer from existing disability supports to the NDIS. However, around 90,000 people were accessing NSW disability supports prior to the NDIS rollout. These government estimates therefore showed a potential gap of approximately 11,000 existing clients who could not access the new scheme (Carers NSW, 2018a).

The NDIS evaluation found that the program has been delivering the outcomes it was intended to and has contributed to increased levels and quality of services for its recipients (Mavromaras et al., 2018). However, not all people with disability have experienced beneficial outcomes. Notably, those who are unable to advocate for themselves and those who are not part of the NDIS appear to have missed out (Mavromaras et al., 2018). The evaluation also found that supports for carers and other family members are limited, with high demand for disability supports exceeding supply across the sector, leading to substantial levels of unmet need amongst people with disability and their carers (Mavromaras et al., 2018). The lack of resources to support people with disability attempting to navigate NDIS systems further exacerbates the process, especially in places with fewer service providers such as regional and remote areas (Gallego et al., 2017; Lloyd, Moni, Cuskelly, & Jobling, 2020; Warr et al., 2017).

The Productivity Commission (2011) recommended the Information, Linkages and Capacity Building Program (ILC) be implemented to provide information and referrals to community and mainstream services (e.g., health, education, employment, transport, and housing). This program is vital for the sustainability of the NDIS by reducing reliance on NDIS funded services and enabling other supports to become more effective at helping people with disability achieve their goals (Productivity Commission, 2017).

While the introduction of the NDIS has allowed many people with disability to access individually funded support packages, many others have faced significant barriers. People who cannot access an NDIS package rely on the support of family and friends, which compounds the impact on their carers, who are not only replacing previous formal supports but also missing out on supports for themselves (Carers NSW, 2018a).

These developments have meant there are three main ways in which carers of people with disability may miss out on necessary supports following the implementation of the NDIS.

First, the person with disability may or may not receive sufficient support. This can occur as a result of:

a. not meeting eligibility criteria according to the *NDIS Act*
b. being eligible under the *NDIS Act* but assessed as ineligible due to assessors' interpretations of the eligibility criteria
c. being assessed as eligible but experiencing access delays
d. being assessed as eligible, but unable to access sufficient services due to other problems of availability, accessibility, or inadequacy compared with the situation prior to the introduction of the NDIS
e. being eligible but receiving less funding than they previously received or less than what they applied for to meet their needs.

Second, the person with disability may receive support from the NDIS, although the carer is excluded from input into the assessment process or from any support that may be provided. This can be the result of explicit NDIS assessment procedures or in contravention of them, or because of locally implemented assessment procedures.

Third, carer-specific services have been significantly reduced and restructured, resulting in difficulties for carers trying to access them.

### 1.3.1 Focused carer group studies

Carers NSW (2018a) has identified three main groups of people with disabilities who are at risk of missing out on funded supports under the NDIS:

- people with a mild to moderate disability
- people with chronic illness resulting in disability
- people living with mental health issues particularly those with mild to moderate or episodic disability.

Carers of these three disability population groups are similarly at risk of missing out on necessary supports. Accordingly, this scoping study also extends a special focus to carers of each of these three key groups.

### People with a mild to moderate disability

People with a mild to moderate disability may have difficulty demonstrating a level of impairment that meets the NDIS criteria of ‘permanent and significant’ disability. Furthermore, NDIS funded packages are intended to target people with the most severe disability needs, resulting in people with a less severe disability needing to access supports through the broader service system, including the Information, Linkages and Capacity Building Program (ILC). Examples include individuals with down syndrome, global developmental delay, and Level 1 autism spectrum disorder. While coverage was not universally available to carers or members of each of these groups prior to the introduction of the NDIS, access was obtainable to a range of general social support services under the HACC program, while specialised disability information, advocacy and support services were funded through NSW disability support legislation (Carers NSW, 2018a).

### People with chronic illness resulting in disability

People with serious chronic health conditions that result in disability were previously able to access services via HACC and its replacement program for people with disability under 65 years of age, the Community Care Supports Program (CCSP). But they may now be unable to access current services as they are deemed ineligible for the NDIS. Carers NSW (2018a) suggest that misinterpretations of the NDIS eligibility criteria can result in people with chronic illness being unfairly excluded from the scheme. Common examples include people with cystic fibrosis or multiple sclerosis, and those with serious or terminal illnesses such as cancer. Such individuals may be excluded from NDIS supports due to their conditions viewed as the responsibility of the broader health system (Carers NSW, 2018a). Given the wide range of chronic illnesses that could fall within this category, this report will compare two examples: cystic fibrosis, where many affected individuals are missing out on the NDIS, and multiple sclerosis, where individuals have had more success in accessing the NDIS.

### People living with mental health issues

People living with mental health issues may face barriers in NDIS assessments due to the episodic nature of their disability or difficulties in communicating their support needs (Smith-Merry et al., 2018). The Tune Review of the *NDIS Act* (Tune, 2019) recommended that NDIS legislation be amended to address the issue of assessing the episodic nature of some disabilities. The Tune recommendation is expected to be implemented in legislation introduced to Parliament in 2021. To date, however, people living with mental health issues may have been deemed ineligible for the NDIS if their disability was not considered to have a significant enough impact on their functional capacity (Carers NSW, 2018a). In the NDIS trial sites, approximately 25% of applicants who identified mental health issues as their primary diagnosis were assessed as ineligible, despite many of them reporting that they previously accessed support services subsequently transferred to the NDIS (Carers NSW, 2018a).

### 1.3.2 Eligibility criteria for NDIS participants

It is important to note that under the *NDIS Act* (NDIS 2013) carers are not eligible to receive NDIS funding. Rather, in accordance with the basic principles of the act, funding is allocated to eligible individuals with disabilities to

> ‘Respect the interests of people with disability in exercising choice and control about matters that affect them, [to] enable people with disability to make decisions that will affect their lives, to the extent of their capacity; and ... support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.
>
> (NDIS, 2013: Section 17A [3]).

To access a funded NDIS package, people with disability must meet the existing eligibility criteria, including:

- age (under 65 at the time of making an access request)
- Australian citizenship or permanent residency
- evidence of functional, permanent and significant disability, or
- meeting the requirements for early intervention set out under the Act. (NDIS, 2013).

The disability requirements set out in the *NDIS Act* as amended (see Appendix A) play a key role in people with disability and their carers being able to access necessary supports. The *NDIS Act* also provides for early intervention requirements when they are likely to reduce a person’s future needs for supports.

Carers NSW (2018a: 14) have reported that ‘eligibility criteria were not always applied consistently, were subject to change over time, and could be appealed.’ Skills and training gaps exist among assessors, and errors have been reported due to rushed processes. Similarly, the Productivity Commission (2017) reported that planners often do not have enough specific disability knowledge, particularly in relation to certain diagnoses, which include progressive degenerative diseases (such as motor neurone disease and dementia) and autism.

Given that the eligibility criteria are the main factor influencing how people are able to access individualised supports, the Productivity Commission (2017: 20) argued that these criteria must be ‘clear and rigorously upheld’.

### 1.3.3 Carer Gateway

The Carer Gateway is intended to provide carers with access to a range of individually tailored supports and services. As of July 2019, support for carers was made increasingly available through the Carer Gateway website. The assistance includes telephone counselling, online peer support, online coaching, and educational resources. From April 2020, a national network of Carer Gateway service providers has also provided services to carers, including needs assessments and planning, counselling and peer support, targeted financial support packages, information and advice, emergency crisis support, and assistance with navigating local services. Eligibility for the Carer Gateway is intended to be broad to ensure carers who support someone ineligible for the NDIS are not disadvantaged. The extent to which this has been achieved has not yet been investigated in detail and could not be assessed in this report, as data collection took place prior to the establishment of the Carer Gateway.

## 1.4 Research for the scoping study

To make the most of limited resources, this  project was designed to use reliable, publicly available demographic and administrative data on carers and access to support services by those for whom they care. To shed light on the personal circumstances of carers and their family members and to capture the perspectives of a number of experienced senior service providers before and after the introduction of the NDIS, a number of in-depth interviews and case studies were also undertaken.

The research design involved four distinct data collection and analysis processes:.

1. **Quantitative demographic analysis:** Population estimates of carers and people with disability were conducted. *The Survey of Disability, Ageing and Carers* (SDAC) (Australian Bureau of Statistics) was the primary data source, and was supplemented with other sources (see Appendix B).

Using existing data from the ABS and the NDIS, this report seeks to provide estimates of the number of people with disability and their carers missing out on essential supports. Other reliable survey data from Carers NSW has also been used to shed light on carers' access to services and support.

2. **Sector expert consultations:** Consultative interviews were conducted with 15 sector experts in the NSW disability and health sectors.
3. **Service provider interviews:** Interviews were conducted with 10 service providers involved with the three in-depth focus populations of this project.
4. **Carer case studies:** Six carer case studies were developed with representation from each of the three focus populations of the project (see Appendix C). Those interviewed volunteered to participate in the study.

The qualitative interviews with sector experts and service providers were designed to explore the impact of the restructuring of disability support in NSW on service provision, individual carers and their families.

Although it was not possible to select and interview a larger sample of carers, service providers or sector experts for this study, key informant interviews serve to illustrate the outcomes of the move to the NDIS and the abolition of the pre-existing state-funded system of support services on those carers who have missed out on support as a result.

More detail regarding the research approach and methods is provided in Appendix B.

Findings from each of these stages are presented in the following sections of this report. The results are discussed collectively, identifying implications for the ongoing support of carers of people with disability under the NDIS in the concluding sections of the report, Sections Five and Six.

# 2. Demographic analysis

Data for the demographic analysis were primarily drawn from the 2015 and 2018 iterations of the *Survey of Disability Ageing and Carers* (SDAC) undertaken by the Australian Bureau of Statistics. As the NDIS was rolled out in NSW from 2016, these surveys enable a comparison between time points immediately preceding and directly after the NDIS rollout. The changing nature of the disability service landscape over this time is likely to have had some effect on the data presented in this section. The analyses do not infer a causal effect of the NDIS for carers. Rather, these findings highlight issues of unmet need at these two distinct time points. It should also be noted that the full rollout of the NDIS in NSW occurred in 2018, so some eligible people may not have accessed a package at the time of the SDAC data collection earlier that year.

The demographic analysis provides estimates on:

- the population of carers in NSW
- the number of primary carers supporting people with disability aged 0–64 years (i.e., meeting the age criteria for the NDIS)
- the proportion of carers reporting a need for additional support or unmet needs.

The analysis also estimates the proportion of people with disability in NSW receiving formal[iv] and informal[v] assistance, and the proportion needing more support. These analyses provide broad estimates of the number of carers in NSW who are missing out on necessary supports.

SDAC provides information on four levels of disability severity:

1. profound limitation: people who are unable to do an activity
2. severe limitation: people who sometimes need help or have difficulty
3. moderate limitation: people who do not need help but have difficulty
4. mild limitation: people who do not need help or have difficulty but use aids or have limitations.

This classification is separate from diagnoses (e.g., chronic illness, mental illness, and psychosocial disability). Data regarding carers of people with specific diagnoses are presented in later sections of this report to illustrate issues raised in consultations with sector experts. It should also be noted that much of the data collected and reported by the NDIA does not distinguish between different groups of disability or accurately report co-occurring conditions (Bigby, 2020).

## 2.1 Carers in NSW

In 2018, there were an estimated 854,300 carers in NSW supporting care recipients of all ages or 10.8% of the NSW population (ABS, 2018a). This is a slight decrease from 904,400 carers in 2015 or 12.1% of the NSW population (ABS, 2015a).

Approximately one in three of the 854,300 carers in NSW, or 32.1%, were primary carers[vi]. Of these, the ABS estimates 131,862 were primary carers providing ongoing care and support for someone with disability aged 0–64 years. The majority (95.4%, over 125,000 in total) of the primary carers of people with disability in NSW provided support to someone with a severe or profound disability. Around one in twenty, 6,066 carers (4.6% of the total) were reported as providing care for a person with a mild to moderate disability (ABS, 2018b). Note that detailed ABS data regarding caring situations is only available for primary carers, and therefore excludes other (non-primary) carers as they are not captured in SDAC data.

### Table 2.1 ABS Population estimates of carers in NSW (n)

| | 2015 | 2018 |
|---|---|---|
| All carers[1] (all ages) | 904,400 | 854,300 |
| All primary carers[1] | 278,700 | 273,900 |
| Primary carers of person aged 0–64 years[2] | 134,055 | 131,862 |
| Primary carers of person aged 0–64 years with a severe or profound disability[2] | 128,702 | 125,796 |
| Primary carers of person aged 0–64 years with a mild-moderate disability[2] | 5,353 | 6,066 |

1 Source: ABS (2015a) and ABS (2018a)

2 Source: ABS (2015b) and ABS (2018b)

In 2018, 59,133 primary carers of people with disability aged 0–64 years in NSW reported needing more support in their responsibilities for caring for a family member, partner or friend (Table 2.2). This was 44.8% of all primary carers and a significant increase from the 36.0% (n=48,308) who reported needing more support in 2015.

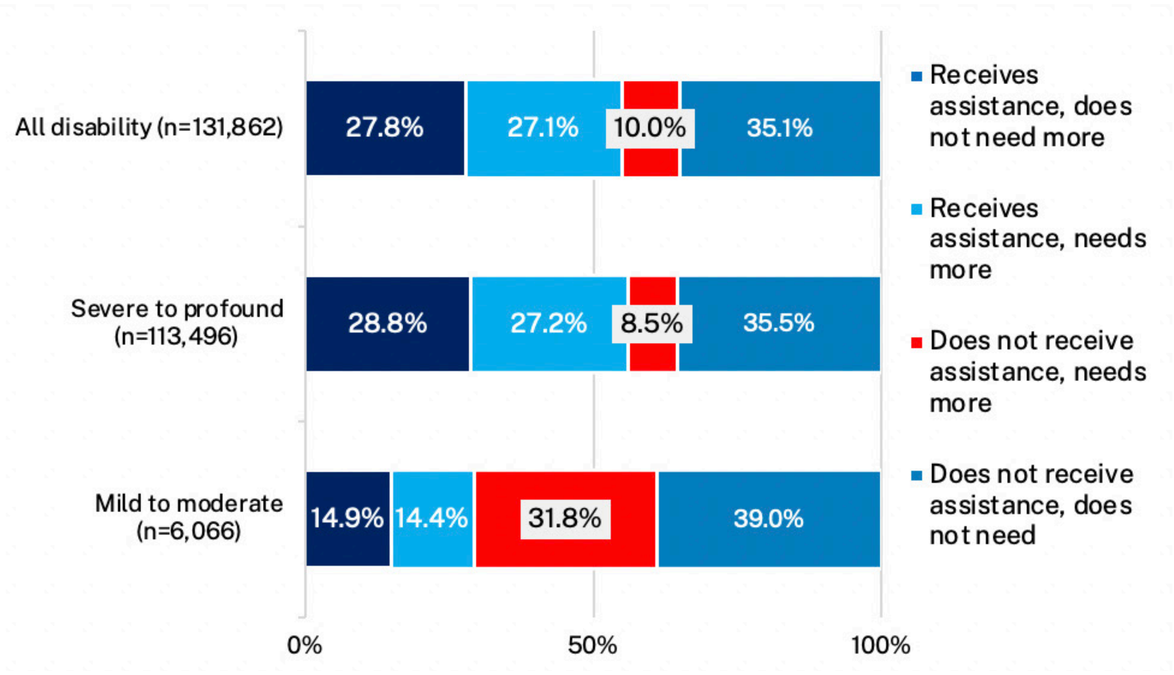
### Table 2.2 ABS data on Primary Carers of persons aged 0–64 in NSW, 2015 and 2018 by response to Question on need for Support

| | 2015 | 2018 |
|---|---|---|
| Primary carers of person aged 0–64 years | 134,055 | 131,862 |
| Needs improvement or more support to assist in caring role | 48,308<br>(36.0%) | 59,133<br>(44.8%) |

Source: Analysis of confidentialised unit record files datasets – ABS (2015b) and ABS (2018b)

Among primary carers of people with all levels of disability aged 0–64 years in NSW, 37.1% reported a specific need for more assistance (see top row, Figure 2.1). This included 10.0% of all disability carers who did not receive any assistance from formal services whatsoever, and 27.1% who received some assistance but reported that they needed more.

Figure 2.1 Assistance needed and received among primary carers of people aged 0–64 years with disability in NSW



Source: ABS (2018b)

Carers of people with mild to moderate disability were less likely to receive assistance than those caring for people with severe to profound disability (Figure 2.1). It should be noted the population of primary carers of people with severe to profound disability was substantially larger than the population of primary carers of people with mild to moderate disability. Therefore, while a larger *proportion* of primary carers of people with mild to moderate disability reported a need for assistance (46.2% vs. 35.7%), a much larger *number* of primary carers of people with severe to profound disability reported a need for assistance (40,592 vs. 2,799).

Table 2.3 outlines the unmet needs of primary carers of people aged 0–64 years with disability in NSW in 2015 and 2018 (ABS, 2015b; ABS, 2018b). Financial assistance was the most commonly reported unmet need at both times. Unmet needs related to carers' health, emotional support, and educational courses were all more prevalent in 2018 than in 2015. Conversely, unmet needs for respite and physical assistance were less common in 2018 than in 2015. The estimated proportion of primary carers with any unmet need increased from 36.5% in 2015 to 44.4% in 2018.

### Table 2.3 Unmet needs of primary carers of people with disability aged 0–64 years

| Unmet needs reported by primary carers | 2015 | 2018 |
|---|---|---|
| Need financial assistance | 36,632 (27.3%) | 40,349 (30.6%) |
| Need improvements in own health | 21,458 (16.0%) | 29,526 (22.4%) |
| Need emotional support | 20,959 (15.6%) | 27,023 (20.5%) |
| Need respite | 23,168 (17.3%) | 18,893 (14.3%) |
| Need physical assistance | 18,408 (13.7%) | 17,640 (13.4%) |
| Need education/courses | 10,661 (8.0%) | 17,138 (13.0%) |
| **All unmet need** | **48,900 (36.5%)** | **58,542 (44.4%)** |

Source: ABS (2015b) and ABS (2018b)

## 2.2 People with disability in NSW

In 2018, there were an estimated 1,346,200 people with disability (all ages and all levels of disability) in NSW or 16.9% of the NSW population (ABS, 2018a). This was a slight decrease from the 1,372,400 people estimated in 2015 or 18.1% of the NSW population (ABS, 2015a).

In 2018, 841,300 people with disability in NSW needed assistance with a broad activity area. Of those needing assistance, 73.3% received informal assistance and 53.5% received formal assistance. Nearly one-third (32.3%) reported a need for more formal assistance. Among those receiving informal support, 31.9% needed more formal assistance (n=197,000). The estimated number of people with disability in NSW, their needs for assistance, and receipt of formal and informal assistance between 2015 and 2018 is shown in Table 2.4.

### Table 2.4 Estimated number of people with disability in NSW (all ages) and their assistance needs

| | 2015 | 2018 |
|---|---|---|
| **People with disability (all ages)** | 1,372,400 | 1,346,200 |
| Needs assistance with broad activity area | 844,300 | 841,300 |
| **Of those needing assistance with broad activity area:** | | |
| Receives any informal assistance | 633,900 (75.1%) | 616,900 (73.3%) |
| Receives any formal assistance | 430,600 (51.0%) | 450,000 (53.5%) |
| Needs more formal assistance | 230,000 (27.2%) | 276,100 (32.8%) |
| **Of those receiving informal assistance:** | | |
| Needs more formal assistance | 181,100 (28.6%) | 197,000 (31.9%) |

Source: ABS (2015a) and ABS (2018a)

In 2015 and 2018, substantially more people with disability received informal assistance than formal assistance. In 2018, 32.8% of people with disability needed more formal assistance, which increased from 27.2% in 2015. The need for more formal assistance also increased among those who received informal assistance, from 28.6% in 2015 to 31.9% in 2018.

A similar pattern was found among those people with disability who were aged 0–64 years (Table 2.5).

### Table 2.5 Estimated number of people aged 0–64 years with disability in NSW and their assistance needs

| | 2015 | 2018 |
|---|---|---|
| **People with disability aged 0–64** | **773,900** | **720,000** |
| Needs assistance with broad activity area | 453,800 | 429,000 |
| **Of those needing assistance:** | | |
| Receives any informal assistance | 381,400<br>(84.0%) | 347,300<br>(81.0%) |
| Receives any formal assistance | 234,400<br>(51.7%) | 230,800<br>(53.8%) |
| Needs more formal assistance | 179,600<br>(39.6%) | 179,200<br>(41.8%) |
| **Of those receiving informal assistance:** | | |
| Needs more formal assistance | 127,500<br>(34.4%) | 121,600<br>(35.0%) |

Source: ABS (2015a) and ABS (2018a)

According to these results, in 2018 there were an estimated 121,600 people aged 0-64 years with disability in NSW who received informal assistance but needed more formal support. This need for additional formal support has important implications for the carers providing informal support. As indicated in the case studies presented later in this report, carers often take responsibility for overall support needs, frequently at a cost to their own finances, health and their opportunities for social engagement and a career.

## Comparing SDAC and NDIS participant data

According to NDIS data, there were 113,590 active NDIS participants in NSW as of 31st December 2019. Of those, 110,004 were aged between 0–64 years and 3,586 were aged 65 years or over. In Table 2.6, NDIS administrative data and 2018 SDAC data are combined to compare the number of active NDIS participants with population estimates of people needing assistance on the basis of disability.

### Table 2.6 Number of active NDIS participants in NSW compared to ABS population estimates of people aged 0-64 years with disability needing assistance (Dec 2019)

| | Needs Assistance[1] | | | Active NDIS Participants[2] | Percent Accessing NDIS Package[3] |
|---|---|---|---|---|---|
| | Mild/Moderate Limitation | Severe/ Profound Limitation | All | | |
| **Age** | | | | | |
| **0–14 years** | 11,400 | 61,600 | 80,300 | 45,491 | 56.7% |
| **15–24 years** | 18,900 | 33,100 | 62,100 | 19,320 | 31.1% |
| **25–64 years** | 128,600 | 124,400 | 285,800 | 45,193 | 15.8% |
| **Location** | | | | | |
| **Sydney** | 80,900 | 127,400 | 240,400 | 49,749 | 20.7% |
| **Rest of NSW** | 79,400 | 89,400 | 186,900 | 63,825 | 34.1% |
| **Total** | **160,300** | **217,500** | **429,000** | **113,590** | **26.5%** |

Note: Numbers in this table do not add up to row and column totals due to missing data and standard error of population estimates generated by TableBuilder.

1 Needs assistance or has difficulty with broad activity area. Source: ABS (2018a)

2 Source: NDIS participant data, December 2019

3 Percentages reflect the number of active NDIS participants as a percentage of total number of people with disability needing assistance.

The number of active NDIS participants in each age group and geographical region is less than the corresponding estimated population of people with a severe or profound limitation. The data shows access to the NDIS is highest amongst the age group 0–14 and lowest for those aged 25–64 years. Similarly, there are important differences based on geographical location in the rate of access to the NDIS. In the Sydney region approximately one in five people (20.7%) with disability reported receiving the NDIS. In the rest of the state, approximately one in three (34.1%) received NDIS assistance. These comparisons do not indicate the extent to which support needs are met for those who do not receive a funded package (e.g., through other service systems). They do, however, highlight the importance of ensuring people with disability and their carers are supported outside of funded NDIS packages.

## 2.3 Summary

The data presented in this section of the report shows there is increasing reliance on the work of unpaid family carers. Strong family carer involvement and unmet need was evident prior to the introduction of the NDIS and continued to exist in 2018.

In 2018, there were an estimated 59,133 primary carers of people with disability aged 0–64 who needed more support in their responsibilities for providing unpaid care to a family member, partner or friend. The number who needed more support had increased considerably since 2015. Significantly, carers were more likely to report unmet needs in 2018 than in 2015. Increases in unmet needs were reported in relation to finances, carers' health, emotional support, and educational courses. At the same time, unmet needs in relation to respite and physical assistance were still significant, although less prevalent in 2018 than in 2015.

Between 2015 and 2018, both the number of people with disability in NSW and the number receiving informal support decreased slightly according to ABS figures. The proportion who reported a need for more formal support remained stable or increased slightly. In 2018, there were an estimated 121,600 people aged 0–64 years with disability in NSW who received informal assistance but needed more formal support. As will be described in the following sections of this report, some of these needs for additional support may be due to changes in the disability service sector landscape during the implementation of the NDIS.

Importantly, the number of active NDIS participants as of December 2019 was considerably less than the estimated population of people with severe or profound limitations. Some people with disability are able to have their support needs met through services outside the disability sector and NDIS (e.g., health, education, transport). The data presented highlight the importance of ensuring the widespread availability of effective support for people with high levels of disability as well as those with mild to moderate disability who do not receive NDIS packages.

These findings suggest that many carers of people with disability continue to provide essential care to a family member, partner or friend with insufficient support from formal services. The following sections present results from the qualitative phases of this project to explore in more detail those situations where carers are missing out.

Section 3 looks at how eligibility for the NDIS operates. It shapes access to care and support for people with disability, and profoundly affects the lives of carers and their opportunities to make choices about their own lives. Section 4 examines the situation of carers from each of the three focus populations identified earlier: carers of people with a mild to moderate disability, carers of people with chronic illness resulting in disability, and carers of people living with mental health issues (particularly mild to moderate or episodic disability). The concluding sections of this report canvas some of the approaches the experts and carer informants for this study suggested, and then proposes a way forward.

# 3 Service Eligibility, Access, and Supply

## Case study – Laura and Michelle (part 1)

Laura, a 70-year-old woman, is the primary carer for her daughter Michelle, who has cystic fibrosis (CF). Michelle is 50-years-old and lives with her husband and teenage son, who also provide care. Laura has been caring for Michelle since she was born. Laura lives near her daughter's family home and usually provides 5–10 hours of support each week, although this increases when her daughter is unwell due to CF.

When the NDIS was introduced, Michelle submitted an application to receive support. Her application included letters from her CF specialist, as well as from her GP, physiotherapist, and social worker. Her first application was declined on the basis that mainstream support options would be able to meet her needs. CF, she was informed, is not considered a lifelong or permanent disability. Michelle said, 'Someone at the NDIS told me I could access mainstream health services. This just isn't an option for daily chest clearance. This service just isn't available. CF is a genetic condition, which makes it lifelong.'

Michelle subsequently made an application to the Administrative Appeals Tribunal (AAT). Before the matter was determined by the AAT, a settlement was reached. This meant that Michelle could access the NDIS and receive funded support. She said while this was a good outcome for her, it meant that others with CF could not refer to her case as an example.

Laura, her mother and carer, said, 'During the appeal process, Michelle was spending around two days each week collecting evidence for her appeal, writing letters, and contacting public officials to advocate for herself and others with CF to access the NDIS.' She also said, 'During this time I did a lot more in my caring role. I could see how much stress Michelle was under, so I did a lot of cooking, cleaning, taking her son where he needed to go, to take some pressure off Michelle.'

The introduction of the NDIS was presented as a major reform that would meet the needs of people with disabilities in a manner and to an extent that had never before been possible in Australia. The NDIS evaluation concluded that the scheme has widely delivered the outcomes it was designed to deliver (Mavromaras et al., 2018). However, its introduction was accompanied by significant changes to support for carers and those for whom they provide care, reflected in major shifts in state and national policy approaches to disability and carer support.

Carers, as a result, have navigated several major changes since the NDIS was implemented. One notable example relates to direct services for carers. One sector expert interviewed for this study summed it up simply, ‘Mainstream supports for carers no longer exist.’

> ‘Mainstream supports for carers no longer exist.’

Other sector experts interviewed also referred to the lack of services available to carers since the NDIS commenced. They acknowledged the potential importance of the Carer Gateway, which had been anticipated for many years but was delayed in implementation. Under the Integrated Plan for Carer Support Services, the Australian Government committed $33.7 million over four years in recognition of the need to support and sustain carers (Department of Social Services, 2018). Sector experts raised concerns about the approach and suggested that effective referrals to the Carer Gateway from the NDIS and mainstream support services should be a priority. However, the Gateway, which commenced operating in April 2020, is focused on providing services such as counselling and mentoring. Sector experts suggested that the extent to which the Gateway is able to replace what was lost from the disappearance of state-based disability services and the NRCP (which has been rolled into the Commonwealth Home Support Programme [CHSP] and targeted towards elderly users) is limited. It is also confined to the relatively small number of carers who receive a Carer Directed Package.

According to the interviewees in this project, the NDIS, which does not have a case finding system, relies on applicants having good informal support networks to assist with access requests, implementing plans and monitoring services. In this sense, the support of carers is paramount to the effectiveness of the NDIS model of disability support. The importance of carers is further highlighted in situations when people with disability are not able to access funded NDIS supports. In such circumstances, interviewees noted that carers must take on additional practical responsibilities for care and providing support, as well as the administrative role of attempting to locate additional support outside the NDIS.

Sector experts (as well as the carers interviewed) suggested that if a person with disability is ineligible for the NDIS, neither they nor their carers are eligible to receive other forms of adequate support. This situation has arisen following the transfer of disability support funding and responsibility for disability support to the Commonwealth Government. The absence of disability support outside the NDIS stood out in the interviews undertaken for this project, despite the recommendation made by the Productivity Commission in 2017 (Productivity Commission, 2017: 29) that the NDIS should not be seen as an 'oasis of support, surrounded by a desert where little or nothing is available'.

In the interviews undertaken for this study, sector experts noted that funding for the previously joint state/Commonwealth funded HACC program had essentially been split into two funding pools: the Commonwealth Home Support Programme (CHSP), for people over 65 years of age, and the Community Care Supports Program (CCSP), funded by the NSW government to provide HACC-type supports to people with disability under 65 years of age.

Following the transfer to the Commonwealth in 2016, CCSP clients were required to demonstrate their eligibility for the NDIS to receive ongoing assistance. This has resulted in many not being able to continue accessing support. Although some funding has subsequently been made available to those who were ineligible for CCSP via NSW Health programs, the extent of support available is limited (Carers NSW, 2019). Sector experts did identify a possible new pathway through which carers may be able to receive some assistance via the Carer Gateway comparable to that which was previously provided under HACC (e.g., domestic assistance). Such assistance is to be provided through a relatively small number of Carer Directed Packages, each valued at up to $3,000 over a 12-month period, with the bulk of successful applicants likely to receive well under this amount. Although none had been made available at the time of this study, sector experts suggested that regardless, the packages were insufficient to provide carers with substantial, ongoing assistance.

Sector experts pointed out that state governments continue to be responsible for the overall wellbeing of people with disability, only a small proportion of whom appear to be able to access the NDIS. Support for people with disability and their carers therefore needs to be considered in relation to mainstream services, including health, education, justice, transport, and housing. The importance of an effective interface between mainstream services and the NDIS was noted by sector experts. This is the purpose of the Information, Linkages and Capacity Building Program (ILC), however, sector experts suggested that Local Area Coordination (LAC) services are overwhelmed with the demands of supporting people to actually implement NDIS plans. This has limited the capacity of the ILC program to develop a wide range of accessible, community-based support services for people with disabilities excluded from the NDIS.

## 3.1 Eligibility and access to the NDIS

Eligibility for the NDIS has been a major issue in the Australian media over the past three years. It was also identified in the policy literature reviewed for this study and was frequently raised in our interviews with sector experts, service providers, and carers. Many people who were receiving NSW government supports prior to the NDIS transitioned smoothly into the NDIS when it started. Conversely, other people with disability continued to experience eligibility barriers. These barriers also profoundly affect carers.

Sector experts reported that many people with disability had been left without adequate formal support, leaving carers to take on additional responsibilities. The case study of Laura and Michelle (introduced at the beginning of this section and provided in full in Appendix C) illustrates the impact of these extra responsibilities. When a person is not eligible for the NDIS, they and their carer are expected to access community level and universal supports. They are directed to Local Area Coordination (LAC) services, funded through the ILC program component of the NDIS, for linkage and referral to local supports. Sector experts suggested that LACs are overwhelmed because of the demands of supporting people to implement NDIS plans, which limits their capacity to assist people with disability who do not receive a funded NDIS package as well as their carers. In addition, carers' ineligibility for their own NDIS packages has reduced the direct supports available to them. For example, the transfer of HACC funding means that some carers have not been able to continue accessing domestic supports.

Other carers interviewed for this project also suggested that advocacy support is key to accessing the NDIS. As Kathryn's case (discussed below) illustrates, without advocacy, people with disability who need support often find the process too difficult to navigate and simply give up. One carer suggested that the system appeared to be designed to 'keep people out' by supporting those who can advocate most strongly for themselves, rather than those most in need. Carers and people with disability may therefore miss out on necessary supports due to difficulties in communicating their needs. Involving carers in planning meetings is essential for ensuring that participants' and carers' needs are met, and that NDIS plans are both relevant and efficient.

## Case study – Kathryn

Kathryn describes herself as a member of the Yorta Yorta and Wemba Wemba Aboriginal communities and has been a carer since she was eight years old. However, she did not identify as a carer until much later. Kathryn described being a carer as ‘just what you do. There is no Aboriginal word for disability, and you just take care of people.’

Kathryn is now in her fifties and has been a carer for five members of her family. As a child, she cared for her mother who has a mental illness and now lives in a nursing home. She also cared for her older brother, Robert, who lived with mental health issues until he passed away. She currently cares for her brother, John, who is one year older than her. John is a member of the deaf community, has epilepsy and regularly experiences depression. Kathryn also cares for her younger sister, Beth, who lives with her and has diabetes. Kathryn has an older sister, Debbie, who also assists John. Beth sometimes stays with Debbie for a few days ‘for a change of scenery’ and to give Kathryn a break.

Her brother John has an NDIS package and lives in a unit he rents. Before NDIS, John did not access any formal supports. Kathryn said John easily got approved for an NDIS package because of his disabilities, but she described the first plan as ‘a disaster’. Kathryn said she was not allowed to be involved in the planning process and so his first plan did not meet his needs. For example, one of John’s goals in his first plan was to get his driver’s licence, but he has epilepsy so he can never drive. The plan included $2,800 to support John to get his driver’s licence. She explained how this experience had been very frustrating. If she had been involved, she believed, her brother’s NDIS package would have better reflected his needs and have actually increased his independence. Not being included in the planning, however, created a lot of extra work and worry for her.

When John’s plan came up for the most recent renewal, he was booked to have a face-to-face meeting with the NDIS planner. The day before the meeting, it was changed to a phone meeting. Phone meetings are, however, difficult for him because of his hearing loss. Kathryn sat with John for that phone meeting and, when needed, she stopped the conversation to explain some of the questions that the planner was asking. She said, ‘If I wasn’t there, he would have agreed to things that he didn’t understand. The person on the phone didn’t check if he understood what was being agreed.’ Because Kathryn was able to be part of this meeting, John’s current plan is far more effective in meeting his needs, she claims. It has also significantly reduced her workload as a carer.

Interview participants described the financial and other hurdles of helping many of those who need assistance as a result of disability gain access to the NDIS. Appointments, assessments and reports from health and medical professionals are essential to provide the evidence required for NDIS eligibility. In addition to the time-consuming work involved, some carers also reported they had to pay or assist with payment of the direct costs involved. This was particularly problematic for those on low incomes. One of the carers interviewed pointed out that those who experience financial difficulties are likely to be doubly disadvantaged if the person they support is subsequently determined to be ineligible by the NDIS.

Service providers interviewed also discussed the administrative burden placed on carers in terms of requesting NDIS access and managing plans or organising supports outside of funded packages. Case management support previously available from agencies such as Community Options under the HACC program aided carers with accessing assistance for themselves or for the person with disability for whom they cared, for example, with contacting health services or assistance with Centrelink paperwork. Service providers argued that the loss of case management support has contributed to a range of unmet needs for carers, particularly those caring for someone ineligible for the NDIS.

Sector experts emphasised that when a participant does access a funded NDIS package, the needs of the carer are ‘seen through the lens of the person with disability’. That is, carers’ needs are not acknowledged independently. They argued that carers need to be recognised in relation to their own needs, circumstances, skills, and strengths. Some sector experts further suggested that block funding could be provided for carer-focused supports such as carer support groups. Although they were hesitant to recommend introducing an additional system, sector experts recommended that an alternative is carers being individually assessed for supports. In raising these concerns, sector experts gave little reference to the Carer Gateway. While these interviews took place prior to the implementation of the Carer Gateway in April 2020, as noted earlier, the lack of reference to its upcoming implementation raises questions regarding the future effective integration of the NDIS and the Carer Gateway.

## 3.2 Respite

In 2011, the Productivity Commission recommended that funding should be made available to provide planned respite for carers who are under great strain and need support. Although it is not regarded as essential for all people with disability, respite is widely considered an essential service for those carers who are isolated and lack family support, as well as those who are under strain. It is also important for co-residential carers who support a person who cannot be left alone for any length of time, such as may occur when a person with disability requiring care has high levels of medical need or exhibits behavioural problems. Because of the episodic nature of some mental illnesses, carers often have to be ‘on call’ and are therefore unable to leave their child without knowing someone else is available. Being ‘on call’ seven days a week takes its toll; the long-term consequence of the lack of access to respite in such cases is often carer breakdown. This may in turn lead to the need for more expensive residential care, so that timely use of planned respite is often understood to be a preventative form of supportive care for both the carer and the person requiring ongoing assistance (O'Brien, 2001).

Access to planned respite under the NDIS has been a concern for carers from the outset, particularly considering the transfer of funding from state-funded respite services and the closure of the NCRP and movement of its funds to the CHSP. Previously, carers in HACC and other funded carer services could negotiate and request when respite took place. This allowed the carer to plan ahead and organise their life.

Sector experts emphasised that early in the implementation of the NDIS, respite was not recognised. They noted this has changed over time, with the phrase 'short term accommodation' now used. Respite can take many other forms, however, including overnight accommodation, in-home respite, and other community-based options. Service providers and carers indicated that the flexible respite options that were previously available no longer exist (Carers NSW, 2021). Although respite is now included in the NDIS price guide under 'social supports', it is only accessible to carers supporting someone with NDIS funding. As Carer Gateway services have commenced, some planned and emergency respite is now within the scope of Carer Directed Support, though these packages are limited to $3,000. This remains, however, well below the amounts previously made available in NSW and unlikely to cover all service provision needed. More detail and analysis of issues associated with the reduced access to respite for disability carers in NSW than can be covered in this scoping study is provided in a recent report from Carers NSW (see Carers NSW, 2021).

As noted in Table 2.3, in 2018 14.3% of primary carers of people aged 0–64 years with disability in NSW reported an unmet need for respite, which decreased from 17.3% in 2015. More detailed analysis of respite need using SDAC data indicates that an estimated 2,256 primary carers of people aged 0–64 years with disability in NSW needed respite within the previous three months but did not receive any (ABS, 2018b). An additional 5,680 primary carers received respite but needed more, and 17,813 had never received respite, despite reporting a need (Table 3.1).

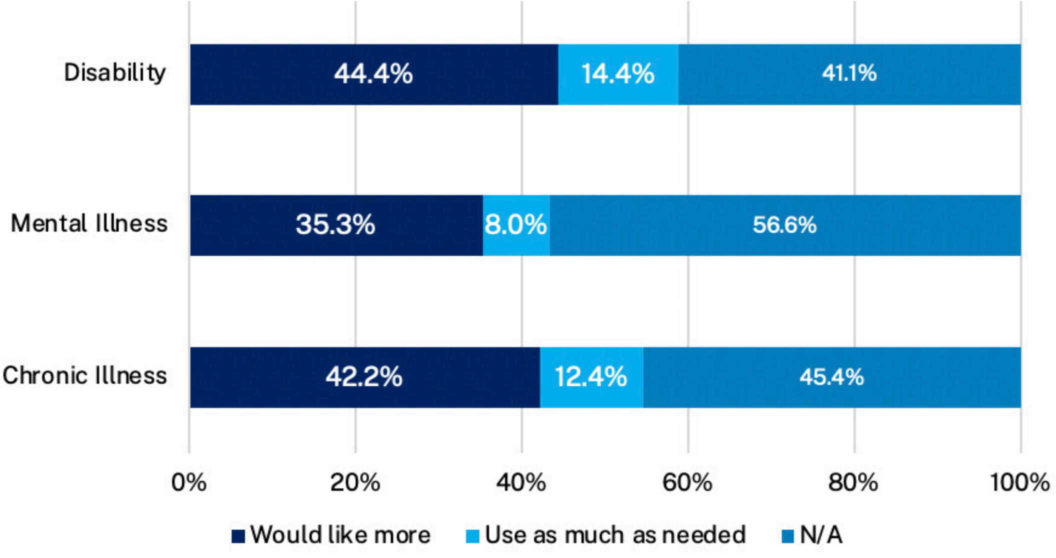
## Table 3.1 Respite need and use among primary carers of people with disability in NSW, 2018

| All primary carers who reported ever needing respite | n | % |
|---|---|---|
| Received respite in last 3 months, did not need more | 3,195 | 9.8% |
| Did not receive respite in last 3 months, did not need it during this time | 3,834 | 11.7% |
| Received respite in last 3 months, needed more | 5,680 | 17.3% |
| Did not receive respite in last 3 months, despite need | 2,256 | 6.9% |
| Never received respite, despite need | 17,813 | 54.3% |
| **Total** | **32,778** | **100%** |

Source: ABS (2018b)

The Carers NSW 2018 *Carer Survey* similarly described that carers reported a substantial demand for more respite, with 44.4% of carers of people with disability, 35.3% of carers of people with a mental illness, and 42.2% of carers of people with chronic illness expressing a desire to access more respite (Carers NSW, 2018b). Significantly fewer carers in each group indicated that they used as much respite as they needed (Figure 3.1).

## Figure 3.1. Carers' satisfaction with access to respite



Source: Carers NSW (2018b)

Sector experts interviewed for this project questioned the concept of NDIS supports providing a 'respite effect' for carers. Because the NDS does not consider carers' needs (Hamilton, Giuntoli, Johnson, & Fisher, 2016), they argued, NDIS supports are not a replacement for respite. Carers who were interviewed agreed, suggesting that funded supports only create a respite effect for the carer when they align with the carer's needs. A common argument identified by sector experts is that respite is most effective where there are high caring demands, i.e., for people with NDIS packages, and that there is not sufficient need outside of that. However, the available data (including that cited above) does not support this argument, suggesting rather that respite is important and highly valued by carers across a range of caring situations (Carers NSW, 2021).

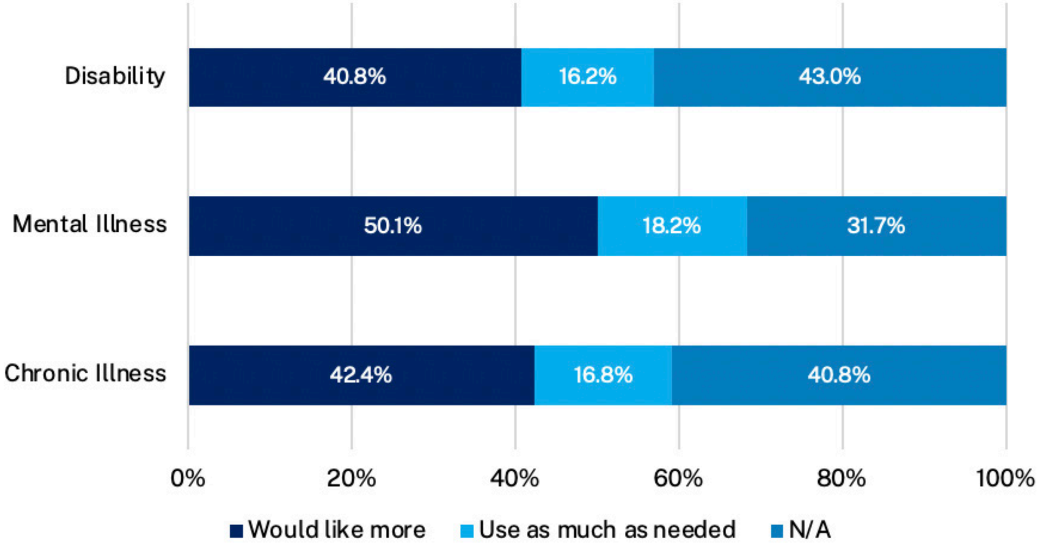
## 3.3 Other specific carer supports

The Carer Gateway has been promoted as a general resource intended to assist carers access supports that are most relevant to them and their needs. Data accessed for this project also identified three key areas of support for carers, including the extent to which they currently meet demands. These supports are counselling, social/peer support (such as carer peer support groups), and financial support.

### 3.3.1 Counselling support

Carers report relatively high unmet needs in relation to counselling services. According to the Carers NSW 2018 *Carer Survey*, 40.8% of carers of people aged 0–64 years with disability would like to use more counselling, as would 50.1% of carers of people with a mental illness and 42.4% of carers of people with chronic illness (Carers NSW, 2018b). Substantially smaller proportions of each group indicated they accessed as much counselling as they needed (Figure 3.2). It should be noted, however, that this data was collected prior to Carer Gateway services becoming available, so carers' access to counselling services may have improved since then.

Figure 3.2 Carers' satisfaction with counselling

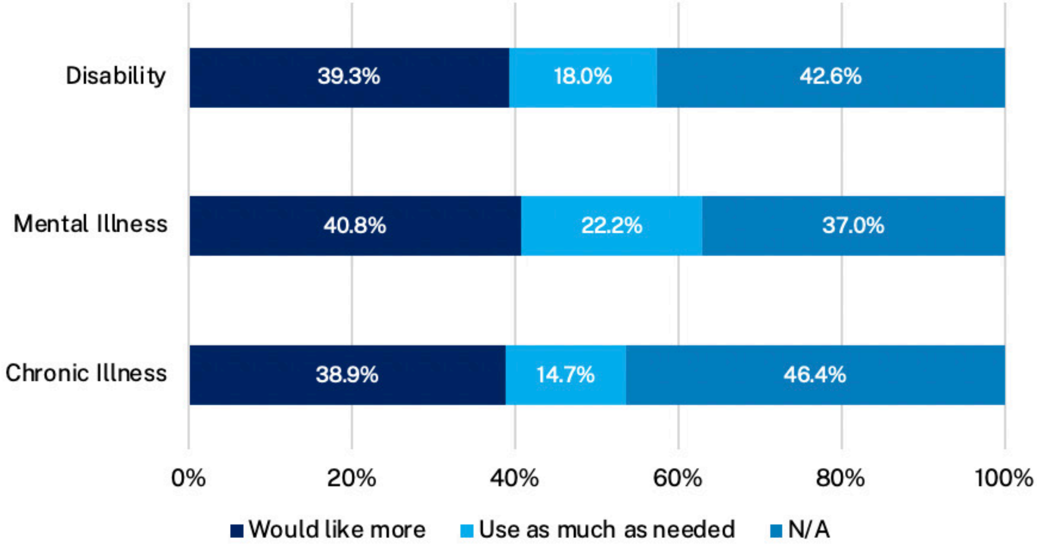


Source: Carers NSW (2018b)

### 3.3.2 Social/peer support

The Carers NSW 2018 *Carer Survey* also indicated that many carers would like to access more peer support: 39.3% of carers of people aged 0–64 years with disability would like to use carer support groups more, as would 40.8% of carers of people with a mental illness, and 38.9% of carers of people with chronic illness (Carers NSW, 2018b). The proportions who used carer support groups as much as they needed was significantly smaller (Figure 3.2).

Figure 3.2. Carers' satisfaction with carer support groups



Source: Carers NSW (2018b)

### 3.3.3 Financial support and legal advice

Given the financial implications of caring for a person with disability, financial supports for carers are critical. Although financial support is not currently a responsibility of the NSW government and has not been so for many decades, the data available shows a significant decrease since 2015 in the number of carers in NSW who receive any care-related payment.

Two main payments are currently provided by Centrelink to assist carers:

1. **Carer Payment:** an income support payment (up to $952.70 per fortnight for singles or $1,436.20 per fortnight for couples) for carers who provide constant care for someone with a severe disability or illness and meet income and asset test requirements;
2. **Carer Allowance:** a fortnightly supplement of $131.90 for carers who meet an income test.

Table 3.2 shows ABS estimates of the proportions of primary carers of people aged 0–64 years with disability in NSW who received the Carer Allowance and Carer Payment in 2015 and 2018 (ABS, 2015a; ABS, 2018a).

**Table 3.2 Financial assistance received by primary carers of people aged 0–64 with disability in NSW**

| | 2015 | 2018 |
|---|---|---|
| Receiving Carer Allowance | 51,965 (38.8%) | 39,154 (29.7%) |
| Receiving Carer Payment | 51,079 (38.1%) | 30,721 (23.3%) |
| Disability carers not receiving either carer allowance or carer payment | 56,603 (42.2%) | 78,773 (59.7%) |
| Disability carers not receiving any income support payment | 31,480 (23.5%) | 51,107 (38.8%) |

Source: ABS (2015a) and ABS (2018a)

The proportion of primary carers accessing each payment decreased markedly between 2015 and 2018. In 2018, 59.7% of primary carers did not receive either the Carer Allowance or Carer Payment. Although many primary carers received other government income support payments, 38.8% did not receive any income support at all. These findings suggest a significant proportion of carers in NSW do not currently access financial supports.

Finally, it should also be noted that under the previous state-based system, carers were receiving a range of supports that were not specifically related to the direct care of their child with disability but would have significant implications for the support they offered. This included support advice and education, such as estate planning, drawing up a will, power of attorney, guardianship and transition from parental care.

## Summary

Sector experts, service providers and carers interviewed for this study each argued that attention is required to address the support needs of carers and people with disability seeking access to NDIS, as well as those who are unlikely to meet the eligibility criteria for assistance and thus remain outside the program. While attention has been placed on people with disability accessing the NDIS, policy level planning across the country should also be extended to address those who remain outside the scheme.

These needs concern access to support for the person with disability. Appropriate assistance for the care recipient clearly helps carers sustain their personal level of support over time. When it is not available, responsibility for providing support typically falls to the carer, in many cases at considerable personal cost. Furthermore, support may also relate to health, education, transport, and other mainstream services for carers themselves.

According to a number of research participants, since the introduction of the NDIS, many people with disability who are not eligible for a funded NDIS package have increasingly found it difficult to receive adequate support from other sources, which has had implications for carers. It is not surprising then that carers in NSW have reported a reduction of support available to them. While some positive examples of transitioning to the NDIS were reported by study participants, as discussed in case studies and in the following section of the report, other examples were described where people with disability and their carers no longer received the assistance they had previously been able to access. They argued that NDIS supports are not an effective replacement for respite. The need for respite and other supportive services beyond NDIS was continually highlighted, which indicates a need for carers to be recognised and supported in their own right, not solely in relation to the needs of the person for whom they care.

In the following section of this report, we look more closely at three such groups of carers of people with disability who have been identified as having low levels of access to the NDIS program.

# 4 Focus population groups

## Case study – Peter

Peter, in his sixties, is the carer for his wife Alison, who is 64 years old. He has been his wife's primary carer for the past 20 years since Alison experienced her first attack of multiple sclerosis (MS). Peter and Alison both have a strong relationship with their two adult children and often spend time with them and their grandchildren. Their daughter also helps her mother, providing emotional support as well as 'picking things up about Alison's health' that her husband might miss.

Peter said it was hard to get any support before the NDIS. After Alison's first hospital stay 20 years ago, they had an occupational therapist visit who arranged for some railings to be installed. They tried to access rehabilitation services after Alison was discharged from hospital and were told that the service was full. This happened again when she had subsequent attacks. Looking back, Peter explained, 'I think it's assumed that you (the carer) will do everything. You don't really have a choice. You just have to get on with it. You're battling because the (health) system is overflowing.'

Around 18 months ago, Peter was speaking to a neurologist who lives in their street. The neurologist has a special interest in MS and knew Alison has the condition, so he suggested they apply for access to the NDIS. This 'chance conversation' was the first time anyone had suggested the NDIS to Alison and Peter. Peter describes the neurologist as 'a lucky find' and the only reason they are now getting support.

Peter said that because they had an advocate at the planning meeting, Alison's NDIS package includes funding for some help with housework, companionship and social support, some equipment so Alison can be more independent at home, and physiotherapy and exercise physiology. Having therapy included was a great relief to Peter and Alison; they were worried about how they could afford to pay for it in the future.

Like Peter's experience prior to his chance encounter with a neurologist, many primary carers and the person they care for miss out on support because they either do not know what support is available or because they are unable to access appropriate support. What really mattered for Peter and Alison was gaining access to the NDIS, which was a pathway to obtaining the ongoing support Alison needed. Since Alison has gained access to the NDIS, Peter is able to continue to care for his wife in partnership with skilled service providers.

This section of the report explores issues related to the three groups of carers that have been selected as requiring more in-depth attention. Carers for each of these groups have been identified as being at particular risk of missing out on funded supports in NSW since the introduction of the NDIS (Carers NSW, 2018a):

- people with a mild to moderate disability
- people with chronic illness resulting in disability
- people living with mental health issues particularly those with mild to moderate or episodic disability.

Interviews conducted for this project provided substantial detail about the experiences of a number of these carers and the people with disability for whom they care, particularly in relation to accessing the NDIS. The interview and other data presented here is based in large part on the subjective personal experience of those who volunteered to contribute. They were not selected as statistically representative of all carers in these circumstances. Their experience is nonetheless informative and is presented as illustrative of experiences that appear to reflect that of other carers, as discussed below. While many of the issues raised are specific to each separate group f carers, they also point to a number of important commonalities that affect many of those carers who currently miss out on support.

## 4.1 Carers of people with mild to moderate levels of disability

Many disabilities vary in their severity. For example, some people with intellectual disability experience mild to moderate limitations. For others, limitations are severe or profound, with significant impacts on every aspect of their lives and on the lives of their carers. A specific diagnosis is therefore unlikely to be sufficient for NDIS eligibility without an assessment of the severity of limitations.

According to the consultations undertaken for this project, people with mild to moderate disability are most likely to be affected in the following situations:

- not meeting eligibility criteria according to the *NDIS Act*
- being assessed as eligible, but unable to access sufficient support compared with their experience prior to the NDIS
- having no carer involvement during the assessment process, excluding carers from input or support.

According to sector experts, people with mild to moderate disability are most likely to miss out on NDIS support because their 'functional capacity', that is, their ability to undertake everyday activities such as showering, dressing, and feeding themself, is not recognised by the assessors as being substantially reduced. Carers of people with a mild to moderate level of disability also miss out due to the targeting of the NDIS towards people with a severe and profound level of disability.

Yet, even if people with mild to moderate disability have comparatively low support needs, sector experts suggested that their carers still commonly provide significant levels of assistance and may in turn require higher levels of support themselves. Carers might not always have to provide high levels of practical support, however, they may need to 'be around constantly'. They also require other forms of assistance, including up-to-date information, advice, peer support, and access to a range of social activities, education and employment both for the person they support as well as for themselves.

A carer's support needs go beyond the functional needs of their child with disability. Under the previous system, the needs of the person with disability included an assessment of their carer's needs and the support available to them. Some carers with a child who had mild to moderate needs had higher needs than those who had a child with more significant needs. For example, a single parent with little family support may require more assistance than those with a partner and other family members who offer support.

In cases involving responsibility for a person with mild to moderate intellectual disability, carers interviewed described how they may take on responsibility for significant parts of their lives, especially administrative matters such as implementing NDIS plans or accessing services outside the NDIS. Carers fulfil this important role because people with an intellectual disability are generally unable to do so independently. Sector experts suggested that carers invest a lot of time in these responsibilities, which limits their opportunities outside caregiving. The impact of lack of carer support, in this way, can have a lifelong impact on the lives of those who take on these responsibilities.

Carers interviewed for this project also emphasised how people with a mild to moderate disability may not identify as having a disability and may not want to access disability services or understand what benefits they may obtain from gaining access to appropriate interventions. This directly impacts carers, particularly by limiting their access to financial or practical support in their caring roles (e.g., through Centrelink or the NDIS). When people with disability choose not to access formal support services for themselves, their reliance on carers remains hidden. It is thus important to enable carers to contribute to assessment consultations in cases involving people with low to moderate levels of disability, as well as to consider carers' needs independently of the needs of those for whom they care.

## 4.2 Carers of people with chronic health conditions

Consultations undertaken for this project suggested that people with chronic health conditions and their carers are most likely to miss out on essential supports for the following reasons:

- not meeting eligibility criteria according to the *NDIS Act*
- being eligible under the *NDIS Act* but assessed as ineligible.

Sector experts interviewed noted that people with chronic health conditions often require disability services as well as health services. Carers also provide disability and health-related assistance and are often required to substitute for ongoing disability support services where the dependent is not able to access them on their own behalf. In many cases, chronic health conditions are assessed as not meeting the 'permanent and significant' NDIS eligibility criteria. As noted by sector experts, this is often due to a failure to recognise significant functional impairments that can result from chronic illness (exemplified in the cystic fibrosis section below). However, sector experts also noted that eligibility criteria for the NDIS does not intentionally discriminate based on the cause of disability. Appropriate interpretation of NDIS eligibility criteria is therefore critical for people experiencing disability as a result of chronic illness as well as for their carers.

Carers interviewed for this study raised the issue of GPs not readily referring people with chronic health conditions to the NDIS. Rather, they argued, many people, including health professionals, appear to assume that carers will take on the responsibilities of supporting ongoing care and/or rehabilitation. Carers suggested health professionals need further education to ensure people with disability resulting from chronic illnesses are referred to the NDIS whenever appropriate.

According to the respondents of the Carers NSW 2018 *Carer Survey*, 61.3% of carers of people aged 0–64 years with chronic illness reported they had been successful in gaining access to the NDIS (Carers NSW, 2018b). However, the available data did not identify specific illnesses or the severity of those illnesses. As noted in the following sections, there are significant inequalities in access to the NDIS between different chronic illnesses. Two specific conditions were selected for this project to further explore the disparate experiences of people with an illness: one that generally receives access to the NDIS (multiple sclerosis) and a second who typically have very limited NDIS access (cystic fibrosis).

## 4.2.1 Multiple sclerosis

Multiple sclerosis (MS) is a condition of the central nervous system for which there is currently no known cure. There are, however, treatments available to help manage symptoms and slow the progression of the disease. People with MS experience physical disability, which means daily tasks take longer and the person may need assistance to complete them. They may also experience cognitive deficits, which means they require constant companionship to remain safe. Carers take on this responsibility in the absence of other supports, as illustrated by Peter's case study above. MS Research Australia estimates there were 7,682 people living with MS in NSW in 2018 (Ahmad, Palmer, Campbell, van der Mei, & Taylor, 2018) and NDIS data indicates there were 2,066 NDIS participants aged 0–64 years with MS in NSW as of December 2019.

Participants with MS consulted for this project generally did not perceive problems in the eligibility criteria for the NDIS, as applicants were usually able to access funded support packages. This was well-illustrated in Peter's case study, presented at the opening of this chapter. Although his wife Alison experienced delays in receiving access to the NDIS, these were related to administrative issues rather than to the assessment of her disability. While no systemic NDIS access issues were noted in relation to MS, Peter's story also highlights the significant administrative responsibilities undertaken by carers to ensure access to a funded package. Service providers also identified some services that are no longer available to people with MS and their carers since the introduction of the NDIS, including physiotherapy services and periodic respite for carers that had been provided through programs previously funded by the NSW government.

## 4.2.2 Cystic fibrosis

Cystic fibrosis (CF) is a genetic condition which currently cannot be cured. It primarily affects the lungs and digestive system. Excessive mucus develops in the lungs, airways and digestive system, causing digestive and respiratory impairments (e.g., reduced lung capacity), recurrent infections, and irreversible damage to their lungs. Reduced lung capacity can have significant effects on the ability of people with CF to communicate verbally (due to breathlessness and/or uncontrollable coughing), work, perform domestic tasks, and participate in the community more broadly. From birth, people with CF undergo constant medical treatment and physiotherapy, including airway clearance.

Service providers and carers interviewed for this study suggested that people who experience disability resulting from CF have difficulty accessing the NDIS, even if they had previously received HACC funded support. Some people with CF have been advised they do not meet the NDIS eligibility criteria as it is 'not a lifelong condition', despite CF's status as a genetic condition that cannot be cured. Sector experts suggested that NDIS planners may automatically refuse NDIS funding because they fail to recognise the serious functional impairments that can result from CF (e.g., mobility, verbal communication due to breathlessness or uncontrolled coughing, and community participation more broadly). Carers reported examples of people with CF being declined access to the NDIS, with decisions based on false assumptions that their support needs can be met by mainstream health support options and carers.

Prior to the NDIS, according to interviewees, many people with CF qualified for home and community care services provided through the HACC program. These included in-home nursing, services such as lung clearance, domestic assistance, personal care, social support, home maintenance and case management. Services such as these are vital for people with CF who experience significantly reduced lung capacity. Now that HACC funding has been transferred to the Commonwealth Government, many people with CF are unable to access these supports. As illustrated by case studies such as Laura and Michelle (discussed below), carers have been forced into undertaking or self-funding these tasks on a regular basis, rather than receiving funded support.

## Case study – Laura and Michelle (Part 2 – See also Section 3)

To maintain her job, Michelle needs to stay on top of her health. She said, ‘I already operate at 50% lung capacity so I need to do everything I can to maintain that level. Daily chest clearance is essential for that.’

Laura, her mother and carer, responded, ‘I told Michelle I would do the chest clearance for her every day if it came to that’, but ‘physically, I couldn’t do the chest clearance for an hour, it’s just too tiring. If I had to do it, I couldn’t go away, and it would definitely limit the other things I could do in my own life.’

‘Parents shouldn’t be doing chest clearance for their adult children’, she continued. ‘[The person with CF] should be able to be independent, to make their own decisions about their treatment and support. When family are required to provide extensive daily treatments like chest clearance, it can be detrimental to those relationships. It causes resentment on both sides. It’s an invasion on that relationship.’

Michelle pointed out that because life-expectancy for people with CF has increased since she was a child, more people with CF are living into adulthood, getting married and having children. This means services are needed to support people so they can stay healthy and have a good quality of life. She added, ‘So many people with CF and their families don’t follow through [after NDIS access is declined]; it’s just too hard and too tiring.’

Michelle said that ‘It felt as though the NDIS was set up for me not to get in. Not getting the NDIS would have placed enormous pressure on my marriage and my other family relationships.’

Quantitative data collected for this project did not specify how many people with CF had previously accessed home care services, or how many have since qualified for supports under new schemes. However, the difficulties experienced by people with CF in accessing the NDIS have been identified by *Cystic Fibrosis Community Care* (CFCC), the main community organisation to support people living with CF in NSW. Data provided by CFCC on the number of NDIS applications they supported between 2016 and 2019 is presented in Table 4.1.

### Table 4.1 NDIS applications assisted by Cystic Fibrosis Community Care, 2016–2019

| Year | NDIS Applications | Successful Applications | % Successful |
|---|---|---|---|
| 2016 (from September) | 6 | 1 | 16.7% |
| 2017 | 40 | 2 | 5.0% |
| 2018 | 27 | 6 | 22.2% |
| 2019 (to 15th July) | 29 | 4 | 13.8% |
| **Total** | **102** | **13** | **12.7%** |

Source: Cystic Fibrosis Community Care administrative data

The 13 successful applicants over three years listed in Table 4.1 were each required to submit appeals to seek a review of their initial outcomes. Their disability had not initially been assessed as 'lifelong' according to NDIS criteria. Given the low proportion of successful applications reported by CFCC (only 12.7%), it appears that people living with CF are likely to be assessed as ineligible for the NDIS. Case studies such as Laura and Michelle (presented earlier in this section) indicate that carers may therefore be required to undertake, or privately fund, practical caring responsibilities when the needs of people living with CF are not met through formal supports provided by either NSW Health or NDIS services.

One of the critical supports required by the majority of people living with CF is assisted airway clearance, which many previously received through HACC funded care services. Service providers interviewed reported that funded support for assisted airway clearance is now only available to NDIS participants. They also reported that people with CF who cannot access the NDIS usually rely on family members to provide assisted airway clearance. In most cases, this is not a sustainable arrangement, as illustrated by Laura's and Michelle's case study. Longer life expectancy means that parent-carers are providing support at an older age when they are not physically capable of performing such physically intensive assistance. Carers like Laura also expressed concerns about the detrimental effects on family relationships that can result from relying on family members to make decisions about who provides treatment and support to people with CF.

## 4.3 Carers of people living with mental health issues

Carers, sector experts and service providers consulted for this study suggested that people living with mental health issues and their carers frequently miss out on necessary supports due to:

- reluctance or inability to seek assistance for themselves
- absence of mental health support services that provide ongoing support
- mental health applicants not meeting eligibility criteria according to the *NDIS Act*
- applicants apparently being eligible under the *NDIS Act* but assessed as ineligible due to interpretation of the Act by assessors
- applicants being assessed as eligible, but accessing insufficient services due to availability, accessibility, or inadequacy compared with prior to the NDIS.

Estimating the number of people living with mental health issues who are eligible for the NDIS is problematic due to the lack of a suitable database. Smith-Merry et al. (2018) reported that the *National Insurance Disability Agency* (NDIA) had estimated that 91% of people with severe mental illness would not receive support from the NDIS but would instead have to rely on alternatives. It is clear the participation rate of people with a primary psychosocial disability in the NDIS has remained low, with just 6.4% of scheme participants in 2018 reported as having a primary psychosocial disability. This was less than half the numbers the NDIA had projected. According to NDIS data, as of December 2019 there were 9,568 participants aged 0–64 years with psychosocial disability in NSW. These represented 8.4% of all NSW participants.

Previously, some mental health services in NSW, such as the Personal Mentors and Helpers Program (PHaMS), were block funded but lost this funding when the NDIS was introduced. The former Carer Respite Centres also received specialist funding targeted at carers of people living with mental health issues. Today, many people living with mental health issues who require support must thus continue to rely on mental health services outside of the NDIS (Productivity Commission, 2017; Smith-Merry et al. 2018). However, it is unclear what supports will continue to be available for those who do not meet NDIS criteria (Productivity Commission, 2017). This situation creates uncertainty for carers as they take on additional caring responsibilities when services cannot be accessed, while being unsure about available support options for those they care for or for themselves.

It should also be noted that since consultations were undertaken for this project, a number of initiatives have been implemented to focus on supporting people with a psychosocial disability to access the NDIS (e.g., a NSW Health program of NDIS Mental Health Access officers). The Commonwealth Government has also established a complex support needs pathway to provide specialised support for participants with disability who need more specialised supports due to complex needs, including mental health issues, incarceration or homelessness.

Carers of people living with mental health issues face additional barriers to accessing support. A person living with mental health issues needs to be well enough to consent and engage with the NDIS if they are to access a package, as noted by Graham in the case study presented in Section 1 of this report. When this does not occur, carers may be left without any formal support for themselves or for the person for whom they care. Similarly, some people with episodic mental health issues do not always know about or acknowledge the support a carer gives them. When they are 'in between' episodes they may need minimal support and therefore say they do not need support. Many carers therefore miss out on necessary supports due to not being personally involved in NDIS planning and assessment processes.

Carers and service providers interviewed for this project indicated carers of people living with mental health issues may incur substantial financial costs in establishing their claims, as illustrated in Melanie's case study (see Appendix C). These costs mostly relate to paying privately for mental health services, such as Medicare gap payments for private psychiatrists and psychologists. Carers also noted that accessing free services for people with psychosocial disability is problematic, particularly for those living in regional and remote areas. These issues highlight some of the impacts on carers when people living with mental health issues do not access the NDIS, resulting in more substantial caring roles and/or incurring potentially overwhelming financial costs.

## 4.4 Summary

Several common issues were raised across the three groups of carers focused on in this project. Each group faces the possibility of those they care for not meeting the eligibility criteria for the NDIS. People with chronic health conditions resulting in disability and those living with mental health issues are clear examples of potential ineligibility, despite meeting the NDIS eligibility criteria. It is important NDIS assessments are conducted by people with an adequate understanding of the disability being assessed, so no one is excluded from the NDIS due to misinterpretations of the eligibility criteria.

The importance of carer involvement in NDIS access requests and planning was also evident across all three groups. People with mild to moderate disability and people living with mental health issues may not identify with having a disability and may not want to access support services. Consequently, these individuals and their carers may miss out on necessary supports if carers are not involved in application processes to act in an advisory or advocacy role on behalf of the person for whom they care.

Under each of these circumstances, there are clear implications for carers. Carers may be left with full responsibilities for providing support when the person with disability is unable to access assistance from the NDIS. Since the introduction of the NDIS, many basic disability services are no longer available. The situation also raises significant issues for ageing carers who are the primary support for a person with disability who is not receiving NDIS services, such as who will look after their child when they either pass away or are unable to provide support due to their own health issues. Such circumstances create additional financial, physical, and relationship burdens that are frequently not sustainable, with significant long-term consequences for those who require support as well for carers.

Given the implications for these three groups of carers when those they care for face barriers to accessing the NDIS, it is important to consider how they can be directly supported as carers. The following section outlines some of the services currently available to carers and those that have been proposed.

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# 5. Next Steps. Where to from here?

In interviews, sector experts, service providers, and carers reflected positively on the support many carers and the person for whom they care had received from services that were previously available in NSW. Since the introduction of the NDIS and the transfer of disability and HACC funding to the Commonwealth Government, most of these are no longer in operation. In their place, the Carer Gateway has been developed at Commonwealth level to assist carers.

In this final section of the report, we draw on the evidence presented earlier to discuss some of the possible ways in which carers of people with disability could be better supported in the exercise of their care responsibilities. We consider first the potential of the Carer Gateway to address these issues, then extend the discussion to consider other potential responses. Recognising the limitations of the data available in this scoping study, we also take the opportunity to briefly discuss the importance of future data collection and research in NSW.

## 5.1 Carer Gateway

The Carer Gateway provides a framework that is intended to provide all carers across Australia with access to a range of tailored supports and services. Eligibility for the Carer Gateway is intended to be broad, reflective of the Commonwealth's *Carer Recognition Act 2010*. The intent behind this broad eligibility is to ensure carers who support someone who is ineligible for the NDIS are not disadvantaged.

As of July 2019, online services were made available for carers through the Carer Gateway's website, including telephone counselling, online peer support, online coaching, and educational resources. This was extended in April 2020, when a national network of Carer Gateway service providers commenced providing tailored services to carers, including carer needs assessment and planning, counselling and peer support, financial support packages, information and advice, emergency crisis support, and assistance with navigating local services. It is also planned to make 'coaching' available from July 2021.

Under the Carer Gateway, some planned and some emergency respite has now also been made available within the scope of *Carer Directed Support*. Although the funding available through *Carer Directed Packages* can be used to apply for domestic assistance, transport, or planned respite, the packages are set at a maximum of $3,000 and are generally much lower than this, so are unlikely to be sufficient to provide ongoing support for carers.

When interviews were conducted for this project, the Carer Gateway had not been fully rolled out. The National Community Connector Program (NCCP) has been established for populations who may need additional support to access the NDIS, namely Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse communities, people living with mental health issues, and ageing parents/carers of people with disability. Additional funding has been committed to expanding the NCCP.

It will be important to monitor carers' experiences over time to determine whether those outside the NDIS are able to access the supports they need. An evaluation of the Carer Gateway has commenced, but no data or other findings are currently available.

Is it possible to separate the issues faced by carers from those of the person they assist? Some sector experts interviewed for this study identified the Carer Gateway as a potential solution to the issue of there being no support pathway for carers until now that is independent of NDIS participants' needs. Focusing more on its limitations, one described it as an 'homogenous solution', suggesting it would not and could not address the needs of all carers. Almost all those consulted for this study pointed to a need for much closer integration between systems set up to assist carers and people with disability.

While the Carer Gateway provides a safety net for those carers who require information or counselling and other forms of individualised support, it falls short in a number of other ways. Importantly, it does not recognise the longer standing care relationship between carers and those who need disability support, nor help carers at the point at which the eligibility for assistance of the person for whom they care is being determined by NDIS planners. In addition, the range and amount of support services available to carers has been greatly reduced in comparison with those previously available.

## 5.2 Current policy options

Both demographic and interview data for this project demonstrates that many carers currently experience a range of barriers to accessing services. A significant proportion currently receive no social support or assistance themselves. Increasingly, those for whom they care need more assistance than they currently receive. Data from the ABS presented earlier shows that significant gaps in support remain even after the introduction of the NDIS. Qualitative evidence from interviews with sector experts and carers suggests such gaps have been a direct result of changes to disability and carer services. These are linked in many cases to the introduction of the NDIS, the closure of the previous state funded disability support system, and the transfer of the HACC program to the Commonwealth.

Under recent policy reforms, many pre-existing carer support services in NSW have closed. While some of their functions have been transferred to the Carer Gateway, as discussed above, the range of existing support options for carers appears to have significantly narrowed.

### 5.2.1 The NDIS

The introduction of the NDIS in NSW has been a positive development for many people with disability and their carers. However, this has not been the case for all. The NDIS evaluation suggested that poorer outcomes have been most notable among people with disability who are unable to advocate for themselves and those who have not been able access the NDIS (Mavromaras et al., 2018). Carers, however, have been significantly affected too. Those responsible for an NDIS participant experience increased demands for management and administrative responsibilities, while those providing for someone who is not a participant in the NDIS are liable for ongoing supervision and support with little if any formal support.

Many people with disability and their carers are missing out on the supports and services they need. Estimates presented in Section 2 of this report show that 121,600 people with disability aged 0-64 years in NSW are not currently receiving sufficient formal supports. Similarly, 59,133 primary carers of people with disability aged 064 years in NSW need additional support with caring. When people with disability do not have their support needs met through formal services there are significant implications for their carers.

The results of this project also highlighted:

- the importance of clear and unambiguous recognition of carers in the NDIS, and of the need to consult with them where applicable
- the consequences arising from the erroneous exclusion of people from the NDIS who are in fact eligible, as assessors fail to consider the functional limitations caused by those experiencing chronic illness and chronic mental health problems
- the lack of support for people with mild to moderate disabilities within the NDIS and for those who remain outside it; the absence of such support has significant impacts on the functional capacities of applicants to remain personally independent, which then has a direct impact on their carers
- the impact of chronic health issues, particularly cystic fibrosis, and the consequences for carers who are denied support from either the NDIS or any suitable alternative service
- the impact of the disabling aspects of mental health issues on carers who continue to take responsibility for support and supervision in the absence of formal support services.

Some of these problems can be addressed through improvements to the operation of the NDIS. There is also a need to improve the interface between service sectors, especially health, disability, and mental health. It is also important for the NSW government to ensure that those who are unable to be assisted through the NDIS will have other alternative pathways to assistance, as discussed in the final section of this report.

### 5.2.2 Support for carers of people with disability beyond the NDIS

A central concern raised in this project is that of people who previously received services but are now deemed ineligible for the NDIS. The results indicate that some people with disability and carers outside the NDIS appear to be worse off since its implementation. Despite the intention for people with disability who are unable to access the NDIS to be able to access supports through mainstream services, significant service gaps have been identified.

The *NSW Carers Strategy 2020–2030* (DCJ, 2020) outlines the NSW government's commitment to supporting carers. The priorities set out under this strategy aim to improve carers' access to information, services, and supports; increase carers' recognition, respect, and empowerment; improve carers' financial wellbeing and economic opportunities; and improve carers' health and wellbeing. This suggests a need to ensure carers can access supports in their own right, regardless of the NDIS eligibility of those whom they support. The strategy notes that the Commonwealth Government is responsible for the Carer Gateway and the NDIS but also acknowledges the NSW government's responsibility to carers under the NSW *Carers (Recognition) Act 2010* and a commitment to monitor carers' access to services. Ensuring carers can have their own support needs met is an important priority raised in the strategy. The results of this project highlight groups of carers who are at risk due to such supports not existing within the current service sector landscape.

There is a need to invest in support services outside funded packages for both people with disability and their carers, including addressing issues of imbalance between supply and demand. Stakeholders indicated that under the previous disability system, many block funded services provided benefits to people with disability and their carers. They suggested that similar services could continue to benefit those who do not have access to funded NDIS packages. Sector experts and service providers recommended that some state-level funding should be retained for programs for people with disability, as other state governments have done, with an emphasis on those who are missing out on funded supports under the NDIS (such as many within the three target groups of this project). Similarly, they suggested that some funding should be provided for targeted carer support services.

The ILC and Carer Gateway were established with the intention of addressing some of the issues identified in this project, such as ensuring sufficient supports are available outside the NDIS, and for providing supports to carers independently of funded packages provided to those for whom they care. Given the lack of data regarding these initiatives available for this project (and the recency of Carer Gateway implementation), the extent to which they are each meeting those goals could not be determined. However, sector experts and service providers argued that greater investment in services for people with disability and their carers outside the NDIS is necessary.

## 5.3 Conclusion. Future research and the direction of carer policy in NSW

This study's scoping of the problem of disability carers missing out in NSW has clearly demonstrated the need for further, more detailed research in the field. The timing of this report and available data also means that it reflects data and service mix available in 2019–20 at a time when the Carer Gateway had been long awaited but not yet fully implemented. The NDIS reached its full rollout stage in 2018, the same year that SDAC and the Carers NSW *Carer Survey* data were collected. Results from these surveys may have captured the experiences of people with disability and carers who had not yet accessed the NDIS but may have done so since. Comparative analyses with future phases of data will enable monitoring of the key issues affecting carers. Additionally, services under the Carer Gateway have been implemented since April 2020. Follow-up research regarding carers' experiences of using these services will be beneficial in determining the extent to which the Carer Gateway, NDIS, and mainstream services integrate to support carers and people with disability.

Due to the limited resources available for this project, consideration of cultural factors affecting Aboriginal people with disability and their carers or those from culturally and linguistically diverse backgrounds could not be considered in-depth. Further research is warranted to explore these issues in greater detail. The scoping study also supported the concerns raised by Carers NSW (2018a) relating to the three population groups at risk of missing out on necessary supports:

- people with a mild to moderate disability
- people with chronic illness resulting in disability
- people living with mental health issues, particularly those with mild to moderate or episodic disability.

These concerns require immediate attention and further research from the NSW as well as the Commonwealth governments.

Since the introduction of the NDIS, a significant number of people with disability and their carers have not received adequate support. There is a demonstrable and urgent need to address the needs of carers of people with disability who are currently excluded from or otherwise falling outside the NDIS.

# 6. Carers Advisory Council Proposal: Diversifying Support

## A recommendation from the Carers Advisory Council (CAC) for a safety net system of basic, easily accessible disability support services, linking people with disability and their carers to basic information and support resources.

In making the NDIS try to meet complex disability needs and control public costs, the scheme gives priority to those who require the highest levels of support. In the process, many people with disability and their carers have been left out. Carers have become 'collateral damage' in the process (Cresswell, 2017), left with the additional responsibilities of supporting a family member, partner or friend, but frequently excluded from consultations with NDIS assessors and service providers.

To address this outcome, the CAC recommends utilising well-tested public health principles to arrange this support in a cost-effective manner (NPHP, 2000). The aim would be to ensure there are a range of support provisions that would be accessible to people with disability and their carers. These would extend from relatively low cost basic information and peer-support services through to the more intensive and costly forms of support provided by the NDIS.

As the research for this scoping study has shown, for many people with disability and their carers, primary support services, the lower rungs of a tiered service system, are either missing or are increasingly difficult to access in NSW. These basic level services act in a preventative manner as a form of primary disability care and support. Such a tier of services should be available to provide basic essential assistance, such as information and peer-support to those with lower levels of need in a manner that will, for many, meet their requirements. The (re)introduction of basic, accessible, community-based disability support services would also prevent the unnecessary escalation of costs, dependency and resource use inherent in the current consumer-focused approach of the NDIS. The sorts of assistance would include many of the forms of support discussed in Section 3 of this report. They include:

- participatory carer social support groups, in which carers share experiences and develop forms of mutual assistance
- information and referral services (in-person and by telephone) that would complement the online resources currently available through the Carers Gateway

- access to some forms of assistance, such as advice on home adaptation and modification
- help with transport, shopping, domestic assistance, home maintenance, and in-home respite
- access to day care and other advice and support services at home and in the community

- basic research and advocacy functions, in which common problems can be identified and remedial response plans developed.

The Carers Advisory Council is convinced primary disability support services developed along these lines are required in addition to other carer friendly changes to the NDIS and Carer Gateway that the evidence documented in this scoping study demonstrates are required.

There is a strong history in NSW of cost-effective and efficient community-based services in this field of human services. Strengthening existing services and developing others where necessary would help prevent cost blowouts in the NDIS at the Commonwealth level and build on the recent positive experience of social collaboration during the pandemic.

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# Appendix A
# NDIS Eligibility Criteria

In order to access a funded NDIS package, people with disability must meet the eligibility criteria, including:

- aged under 65
- Australian citizenship or permanent residency
- permanent and significant disability (NDIS, 2013).

Under Section 22 of the *NDIS Act*, a person meets the age requirements if they are aged under 65 at the time of making an access request. Section 23 of the *NDIS Act* indicates a person meets the residence requirements if they reside in Australia and and are either an Australian citizen, the holder of a permanent visa, or a special category visa (SCV) holder who is a protected SCV holder.

The disability requirements set out in Section 24 of the *NDIS Act* are more complex. They are provided below in full.

### Section 24 Disability requirements

(1) A person meets the disability requirements if:

a. the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition

b. the impairment or impairments are, or are likely to be, permanent

c. the impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities:

    (i) communication

    (ii) social interaction

    (iii) learning

    (iv) mobility

    (v) self-care

    (vi) self-management

d. the impairment or impairments affect the person’s capacity for social or economic participation

e. the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.

(2) For the purposes of subsection 1, an impairment or impairments that vary in intensity may be permanent, and the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime, despite the variation.

The *NDIS Act* also provides for early intervention requirements. According to Section 25, a person meets these requirements when the provision of early intervention supports is likely to reduce the person's future needs for supports in relation to disability. The detailed specifications are set out as follows:

### Section 25 Early intervention requirements

(1) A person **meets the early intervention requirements** if:

a. the person:

   (i) has one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent; or

   (ii) has one or more identified impairments that are attributable to a psychiatric condition and are, or are likely to be, permanent; or

   (iii) is a child who has developmental delay; and

b. the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by reducing the person's future needs for supports in relation to disability

c. the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by:

   (i) mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, selfcare or selfmanagement; or

   (ii) preventing the deterioration of such functional capacity; or

   (iii) improving such functional capacity; or

   (iv) strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer.

Note: In certain circumstances, a person with a degenerative condition could meet the early intervention requirements and therefore become a participant.

The full act is available here: https://www.legislation.gov.au/Details/C2020C00392

# Appendix B

# Research Approach and Methods

The project was divided into four stages, as outlined below.

On behalf of the NSW Carers Advisory Council, the Department of Communities and Justice (DCJ) engaged Nicole Weber Consulting to undertake part of the of the project based on primary evidence from sector experts, service providers, and carers in NSW. A research team from UNSW was subsequently engaged to undertake quantitative analysis of existing data, conduct secondary analysis of qualitative data collected by Nicole Weber Consulting, and consolidate each stage of the project into a single report.

## Quantitative demographic analysis

Potential data sources were scoped and assessed for their relevance and feasibility of contributing to the population estimates required for this project. A summary of included data sources was developed, outlining the target groups specifically identified in each data source and the relevant variables captured within each data source. The identification of appropriate variables was informed by the project brief and in consultation with DCJ and the Carers Advisory Council..

The *2018 Survey of Disability, Ageing and Carers* (SDAC) was the primary data source. Initial analyses were conducted using TableBuilder, while more detailed analyses were conducted using the basic Confidentialised Unit Record File (CURF). Individual level weights were applied to provide NSW population estimates.

## Included data sources

Analysis of 2018 SDAC data was supplemented with other data sources. In most cases, these data sources were publicly available, while further breakdowns of available data were sought from some specific sources.

The following data sources were accessed for this report:

- Australian Bureau of Statistics *Survey of Disability, Ageing and Carers* (2015 and 2018)
- NDIS service user data (aggregate)
- NDIS service provider data (aggregate)
- Carers NSW 2018 *Carer Survey* (additional analysis provided by Carers NSW)
- Department of Social Services Centrelink Payment data (aggregate)
- Disability Services National Minimum Dataset (aggregate)
- Cystic Fibrosis Community Care service data (aggregate provided on request)
- Australian Multiple Sclerosis Longitudinal Study (aggregate).

## Sector expert consultations

Consultations with sector experts were conducted by Nicole Weber Consulting, involving a number of key informants. Sector experts with knowledge and experience of the NDIS planning and implementation processes were identified and approached for individual interviews. Key organisations and their appropriate representatives were initially identified for the disability services consultation phases. Snowball sampling was applied where a core group of contacts were identified and interviewed and asked to recommend other suitable sector experts who could contribute to the project. A total of 15 experts were consulted from 11 agencies in the disability and health sectors.

## Service provider interviews

Nicole Weber Consulting conducted interviews with service providers involved with the three target groups for this research. Interview participants included staff from senior executives to frontline worker roles. Participants were recruited via snowball sampling. Potential participating organisations were identified by members of the project working group and were approached by the researcher via phone and email. An information package was provided as part of an email requesting participation. Participants were also asked to recommend any other service providers to approach for possible participation. A total of 22 service providers were approached, of which 10 agreed to participate, two declined to be interviewed, and 10 did not respond or indicated they were unable to allocate staff with appropriate experience before and after the introduction of the NDIS.

Interviews were conducted via telephone or video conferencing software (e.g., Zoom). Consent was sought from participants to be involved in the project and to record the interview and/or take written notes. All participants were emailed a copy of their written-up interview and asked to approve the content or advise if they wished to make any changes.

## Carer case studies

Six carer case studies were developed with representation from each of the three target groups of the research. Participants were referred directly through the Carers Advisory Council network or via the service providers interviewed. Participants were emailed an information pack and asked to complete an online survey to collect basic demographic information and register their interest. A total of eight carers were contacted, with two determined to be outside the scope of the project.

Interviews were conducted by Nicole Weber Consulting via telephone or video conferencing software (e.g., Zoom). Consent was sought from participants to be involved in the project and to record the interview and/or take written notes. All participants were emailed their written case study and asked to approve the content or advise if they wished to make any changes. At the conclusion of each interview, participants were provided with a gift voucher to acknowledge their time and contribution.

## Ethics approval

All participants provided informed consent prior to participation. At the outset of the project, DCJ advised Nicole Weber Consulting that further formal ethics approval was not required as the project was undertaken according to the guidelines published by Family and Community Services Insight, Analysis and Research Division (2018).

## Qualitative analysis

Summary notes from consultations with sector experts, interviews with service providers, and carer case studies were provided to the research team at UNSW for analysis. These summaries were analysed thematically. Findings from sector experts, service providers, and carers are presented collectively. Where particularly noteworthy, excerpts from carer case studies are provided in the main report.

# Appendix C
# Carer Case Studies

## Case Study 1 – Melanie

Melanie is a 48-year-old woman who lives at home with her family. Currently, two of her four children remain at home as does the children's father, Paul. They live in a small town in rural NSW and are connected to their local Aboriginal community. Three of Melanie's and Paul's children have a disability. The two older children live away from home. Paul has a full-time job, so Melanie provides most of the daily support for Amber (aged 20) and Fin (aged 17), as well as running her own business. Amber and Fin both receive an NDIS package, but Melanie had different experiences in accessing the NDIS for each of her children. Both Amber and Fin were under 18 years of age when they applied, so Melanie was able to make the access requests on their behalf.

For three years before the NDIS started, Melanie was getting support with household cleaning and a respite package for Fin. Both were funded by the Department of Ageing and Disability and Melanie described the support as 'amazing'. When the NDIS started, those supports stopped, but Fin transitioned into the NDIS smoothly.

Fin has a diagnosis of autism which means he has a learning disability and low literacy. Because of his age, he missed out on many funded supports for children with autism. When initiatives were introduced, he was often six months outside the age limit (e.g., for early intervention programs). Melanie said she 'could always find something though' and Fin had a lot of therapies as a child. Melanie and Paul paid for some of these until Fin was four years old and some were later funded by community health and the Department of Education. For three years before the NDIS started, Melanie was getting support with household cleaning as well as a respite package for Fin. Both were funded by the Department of Ageing and Disability and Melanie described the support as 'amazing'. When the NDIS started, those supports stopped, but Fin transitioned into the NDIS smoothly.

Melanie said Fin's NDIS package is now sufficient to meet his needs although they needed to ask for a review to have his funding increased. Melanie self-manages most of Fin's package, apart from an allocation for behaviour support. Fin cannot utilise this allocation though, because the psychologist he sees and trusts is not a registered provider with the NDIS. There are no registered providers of behaviour support within an hour of travel and finding someone Fin can build rapport with is a very challenging process. Fin is currently accessing his NDIS capacity building support to increase his social skills which includes going onto country and learning lore with a trained Aboriginal worker. Melanie is working towards the goal of Fin being able to manage his own NDIS package in the future.

Amber had different experiences in terms of accessing support under the NDIS. Amber has been diagnosed with bipolar 2, borderline personality disorder and post-traumatic stress disorder. She needs support in many areas of life including daily routines, making and attending appointments, preparing meals, and completing household tasks. Melanie describes Amber as socially isolated and reliant on her parents for her social interactions.

Melanie submitted an access request to the NDIS when Amber was 17. At that time, Amber had been hospitalised five times due to her mental health and she was on several medications. Melanie said, 'There was a lot of evidence to support the fact that she had a permanent disability.' This access request was declined. It has taken two access decision appeals for Amber to have an NDIS package approved. As part of the appeals process Melanie was in contact with the complaints team of the NDIS, her local member, and the Minister for the NDIS.

Amber's NDIS package was approved in February 2020. She was allocated a Local Area Coordinator who is a five-hour drive from where she lives. For the past three years, Amber has been seeing a psychologist every week in a bigger town about an hour's drive from her home. Although there is a mental health scheme that provides unlimited access to a psychologist under Medicare, Amber is not eligible for this program, so can only access six subsidised sessions per year. Melanie and Paul pay the full fee ($250 per session) for the remainder of the year. They re-mortgaged their house to fund this as Amber's NDIS package does not include funding for psychological services. Melanie said the psychologist visits 'keep Amber safe and healthy.' Melanie also said, 'I worry about people who don't have access to finances, who can't re-mortgage their house like we have had to do.'

When asked about the barriers to accessing supports under the NDIS, Melanie said doctors and other health professionals need either training or to listen more to carers when it comes to completing NDIS documentation. In her view, 'They don't want to say that the person won't get better, and they won't say anything that could put their reputation on the line.'

The time and cost involved in getting documentation to support an NDIS application was another barrier. Melanie described travelling an hour or more to see a psychologist and paying $250 for a report. She also described waiting at a doctor's office for hours for an appointment only for the doctor not to listen when she explained what information the NDIS needed. Melanie said, ‘The person with the disability and their carer know more about what the person needs and how to write the NDIS application. They’ve done all the research on the NDIS. Doctors and health professionals should listen to them more instead of just writing what they have always written. It’s a new system with new language.’ Melanie went through the process of gathering documentation multiple times due to Amber’s first two access requests being declined.

Melanie expressed frustration and a sense of fatigue in relation to supporting Amber to access the NDIS. She said, ‘You have to play the game – it’s exhausting. There are so many points where you fall over and it’s just too hard. It seems like [the system] is designed that way to keep people out. It’s not necessarily the people with the most need who get the support, it’s the ones who are the most audacious. The NDIS can be great, but I know many stories of people who have just given up.’

When asked about the situation for carers, Melanie said, ‘There is so little support for carers. There are big gaps in information – how do you know about what is out there? I get a lot of information from informal groups on Facebook, by doing hours of research and going down a lot of rabbit holes following links to find resources. People who can get the information get the support.’ Regarding the Carer Gateway, Melanie said ‘I haven’t tried to access the Carer Gateway yet. You have to be mentally able to cope with looking for the information but bad enough to need help. If you ring and say everything is ok at the moment, you won’t get help. But when you actually need the help, you might not have the capacity to ask for it.’

When asked about whether her carer role was recognised in the NDIS planning process, she said, ‘I did include a carer statement, but I only found out about that by chance on a mental health website. The carer statement and the views of the person with disability don’t carry as much weight as the reports from professionals. The doctor only sees you for a short amount of time and when you’re usually putting the best light on your situation.’

Melanie mentioned positive aspects of the NDIS. ‘The idea of choice and control is great. Being able to self-manage is really positive and offers skill-building in a safe way. It means that in time Fin can manage his own support and if he doesn’t get it right straight away that’s ok, he can learn as he goes. The NDIS means I feel less worried for my children in the future.’ .

## Case Study 2 – Kathryn

Kathryn describes herself as a member of the Yorta Yorta and Wemba Wemba Aboriginal communities and has been a carer since she was eight years old. However, she did not identify as a carer until much later. Kathryn described being a carer as 'just what you do. There is no Aboriginal word for disability, and you just take care of people.'

Kathryn is now in her fifties and has been a carer for five members of her family. As a child, she cared for her mother who has a mental illness and now lives in a nursing home. Until he passed away, she cared for her older brother, Robert, who also had a mental illness. Kathryn currently cares for her brother, John, who is one year older than her. John is a member of the deaf community, has epilepsy, and experiences depression. Kathryn also cares for her younger sister, Beth, who lives with her and has diabetes. Kathryn has an older sister, Debbie, who also cares for John. Beth sometimes stays with Debbie for a few days 'for a change of scenery' and to give Kathryn a break..

> Kathryn said she was not allowed to be involved in the planning process and so his first plan did not meet his needs. Kathryn expressed that this was very frustrating because if she had been able to be involved, John's NDIS package would have better reflected his needs and it would have increased his independence. As a carer, not being included in the planning created a lot of extra work and worry about John for her.

Kathryn has three children of her own. Her eldest daughter, Rachel, has autism and was non-verbal as a child. Rachel was not diagnosed with autism until she was nine years old, and she needed a lot of intensive support from speech therapists and occupational therapists as a child. Rachel is now 30 and lives with her boyfriend, who she met at a supported employment program. Kathryn still helps Rachel with paperwork and sometimes goes to doctors' appointments with her. Rachel does not need support from the NDIS because of the work Kathryn did when Rachel was young.

John has an NDIS package and lives in a unit he rents. Before the NDIS, John did not access any formal supports. Kathryn said that John easily got approved for an NDIS package because of his disabilities, but she described the first plan as 'a disaster'. For example, one of John's goals in his first plan was to get his driver's licence, but he has epilepsy so he can never drive. The plan included $2,800 to support John to get his driver's licence. Kathryn said she was not allowed to be involved in the planning process and so his first plan did not meet his needs. Kathryn expressed that this was very frustrating because if she had been able to be involved, John's NDIS package would have better reflected his needs and it would have increased his independence. As a carer, not being included in the planning created a lot of extra work and worry about John.

Kathryn was not able to go to John's first planning meeting because she was working in the disability sector and was told it would be a conflict of interest for her to be there. She found this frustrating because she knew of other people in a similar situation who could attend planning meetings for their children. Even though John is an adult, Kathryn felt John needed an advocate at the meeting. Kathryn said she felt 'cranky' that as a result of her not being included, John's plan did not meet his needs for the next 12 months.

Kathryn gave another example of the results of her not being included in the NDIS planning for John. Before John moved closer to Kathryn 18 months ago he was living in a rented unit in a small city in NSW. He had lived there for nine years. Kathryn wanted monthly social support included in the NDIS plan for workers to go with John to the local shops and introduce him to the staff so they could get to know his needs. Kathryn could see that staff thought John was rude and ignoring them when he went in, because they did not know he had hearing loss. John also had a hard time keeping good relationships with his neighbours because he would turn the television up very loudly. Kathryn thought some social support could help with this too, which would mean John could have stayed living where he was already settled. The social support was not included because John told the planner he was independent and did not need it. Kathryn described John as 'an agreeable person who will go along with whatever is suggested'. She believes this means he will not speak up for what he needs, and so he requires an advocate to support him with things like the NDIS planning process.

When John's plan came up for the most recent renewal, he was booked to have a face-to-face meeting with the NDIS planner. The day before the meeting, it was changed to a phone meeting. Because of John's hearing loss, phone meetings are difficult for him. Kathryn sat with John for that phone meeting and when needed, she stopped the conversation to explain some of the questions that the planner was asking. She said, 'If I weren't there, he would have agreed to things that he didn't understand. The person on the phone didn't check if he understood what was being agreed.' She said the NDIS needs to be aware that phone meetings are not always suitable. Because Kathryn was able to be part of this meeting, John's plan better suited his needs.

John is now on his third NDIS plan. Kathryn has been fighting for the last three years to have a hearing loop included in John's NDIS plan and it has now been approved. She believes it would not have been considered at all if she had not been involved. The hearing loop will mean that John does not have to have the television up so loud, which will improve relationships with family who visit and with neighbours.

Kathryn has only used carer services once or twice. In her work and community roles, she has a lot of contact with other carers. She has worked for NDIS Local Area Coordination services, the education system, and in roles where she has helped people link with support services. Kathryn said she hears from a lot of carers who have been given Access Request information and forms to complete for the NDIS. These carers have told her that the information is hard to understand, and the forms are difficult to fill in so they ‘don’t bother’.

In Kathryn’s experience as a carer, worker and advocate, many NDIA staff don’t understand disability and don’t show empathy. As John’s carer, Kathryn has seen that the episodic nature of mental illness is not always well understood or catered to in the NDIS. She says there is an expectation that family will provide support that is needed by the person. She says that people need to show the NDIS evidence of their ‘bad days’ and this means they are describing and measuring their life according to deficits.

## Case Study 3 – Graham

Graham, aged in his early 60s, is the primary carer for his son, Luke, who recently turned 30. Graham has been Luke's carer since Luke was a teenager. Luke lives with autism and dyspraxia, and experiences extreme social phobia.

Graham provides practical and emotional support to Luke on a daily basis. Luke can take care of some basic cooking and cleaning and ordering groceries online. Graham helps Luke plan healthy meals, prompts him to shower, and takes him to appointments. Luke will not leave the house without Graham because of his social anxiety. Graham worries that Luke is socially isolated. He has a small group of friends that he connects with online, but none in his local area.

Until two years ago, Luke was financially dependent on Graham. When he did apply for Centrelink payments, it took nine months for the Disability Support Payment to be approved. Graham said this is partly because of 'the system' and partly because Luke needs a lot of support to do something new. Luke has never worked, and Graham believes that with the right support to study and gain employment, he could join the workforce. Graham has tried to provide this support himself, but it is challenging as he also has a full-time job.

> Graham worries about what will happen in the future for Luke. Graham would like to see Luke living independently, but Luke would need funded supports for that to happen (e.g., support with social interactions, shopping, study, and maintaining routines).

Before the NDIS was introduced, Luke had no formal support. Graham said they were in the process of applying for the Personal Helpers and Mentors Program (PHaMS) but unfortunately by the time Luke was ready to access the service, the NDIS was introduced, and the service provider could only support people who had an NDIS plan.

Graham said Luke 'doesn't want to meet with an NDIS planner to tell his whole story'. They have completed an access request, but Luke does not want to submit it. Graham spoke about the application process being a significant barrier for Luke: 'In the past you could walk into the office of a service provider and talk to them. The whole process and structure now are a real barrier.'

Graham said 'To organise the NDIS involves a lot of logistics. They need to have a staged approach.' He talked about gathering reports and evidence, and how if access is approved, the person has to meet with a planner and share personal information. He believes this can be particularly overwhelming for someone with a mental illness and a barrier to them getting support.

Graham said he is fortunate his employer allows him some flexibility so he can take Luke to appointments. Getting Luke to an appointment involves making sure he gets out of bed and has enough time to prepare, as well as driving him to the appointment. Graham also has to check when appointments are booked for the future so he can plan his work around them.

Graham is apprehensive about what will happen in the future for Luke. Graham would like to see his son living independently, but Luke would need funded supports for that to happen (e.g., support with social interactions, shopping, study, and maintaining routines).

Graham said he finds it challenging that the NDIS terminology does not recognise the role of a carer, but instead talks about a 'nominee'. Luke has not yet submitted an access request to be considered for the NDIS and his mental health affects his ability to do so. This means there is no support for Luke other than what Graham provides. Graham feels that if he could submit the access request on Luke's behalf, they could try to get some supports for Luke started, which would help Graham significantly in sustaining his caring role. Graham is also aware that Luke would have to appoint him as a nominee, 'otherwise the NDIS won't talk to me'.

Privacy laws mean psychiatrists, psychologists and the NDIS will not share information with carers, even though treatment and services have a big impact on the caring role. Graham feels these laws work well for people who can articulate their needs but create issues when the person with the disability is not able to do so. Graham said there needs to be more awareness about how changes for the person with disability, such as shifts in medication and treatment, impact the carer's life.

When asked about support for his role as a carer, Graham said that before the NDIS he had access to information about carer supports through his role at work. He has always organised his own breaks with informal supports, and he can only go away for a week at a time. Even while he is away, Graham chats with Luke daily to make sure he is ok. This means Graham never gets to 'switch off'. He said, 'It's not how I imagined life would be with a 30-year-old son.'

Graham says he probably would not have known about the Carer Gateway if he did not work in the care sector. He is still looking through the information on the Carer Gateway site.

Graham talked about the NDIS principle that funded supports create a respite effect for carers. He pointed out this is only the case where the NDIS supports align with the needs of the carer. For example, there is no respite effect when a carer needs to attend a regular activity that supports their own wellbeing if the person with disability chooses to have their supports at a different time. Graham acknowledged that the NDIS is intended to be person-centred but argued carer needs should also be considered in planning support or those caring relationships can break down.

Graham said support coordination needs to consider the needs of both the person with the disability and the carer. He said there is so much information on the NDIS website that it creates 'information overload', so Graham would like to see more support available for people to access the NDIS. He said, ‘At the moment, access to the NDIS relies on the person with  disability being capable or having someone to help.’

Graham said he worries about who will help the ‘hidden carers’ in the future. Through his work, Graham was in contact with a lot of older parent carers as part of a program that was funded by the NSW government before the NDIS was introduced. Graham says this was a really important program because it helped identify ‘hidden carers’ and connected them with support and plans for the future. It included practical things like wills and estate planning. Graham expressed the hope that there will be a similar program available through the Carer Gateway.

## Case Study 4 – Peter

Peter is in his sixties and is the carer for his wife Alison, who is 64 years old. He has been a carer for the past 20 years since Alison experienced her first attack of multiple sclerosis (MS). Peter and Alison have two adult children. They have a strong relationship with both of their children. Peter and Alison often spend time with their grandchildren and their daughter provides emotional support and 'picks things up about Alison's health' that Peter might miss.

When Alison had her first attack of MS, it resulted in paralysis of her left side and Peter said, 'She came home from hospital a different person. Even though she looked the same and she felt she was the same person, her personality had changed.' At that time their children were 10 and 12 and Peter said it was hard for all of them to adapt. Alison's family did not live in the area and Peter had to take time off work to care for Alison.

Peter described how he 'took over the cooking, cleaning and all of the household work' as well as taking Alison to appointments with doctors and therapists. Peter still provides this support now. The weakness on Alison's left side means she cannot push a manual wheelchair. They bought an electric wheelchair, but it is very heavy for Peter to get in and out of their home and the car, so they do not use it all of the time.

> The nature of MS is 'up and down' which means Alison's health may decline, plateau, and then decline again. Peter described how daily tasks take longer for Alison to do. For example, if they want to leave the house for an appointment or shopping, it takes at least 45 minutes instead of the five or ten minutes it would take if she did not have MS.

Peter has his own business. He described how he helped Alison to work in the business once she had rehabilitated partially from her initial MS attack. Alison worked at the factory until five years ago. As Alison's health has become worse over the last 10 years, Peter has been working from home more and more. Neurological tests confirmed that Alison is not safe to be by herself. The MS has damaged Alison's memory and ability to make decisions; she has been diagnosed with early-onset dementia. She is not able to make a phone call by herself and she would not be able to call out if she had a fall.

The MS causes some bladder problems for Alison, which means she will often get out of bed three or more times during the night, which also wakes Peter. Alison can also forget if she has been to the bathroom and will get up multiple times within a short space of time. Despite these disruptions, Alison wakes up in the morning and says she 'had a very refreshing sleep', whereas Peter often feels exhausted.

The nature of MS is 'up and down', which means Alison's health may decline, plateau, and then decline again. Peter described how daily tasks take longer for Alison to do. For example, if they want to leave the house for an appointment or shopping, it takes at least 45 minutes instead of the five or 10 minutes it would take if she did not have MS. Peter also described how it is difficult for Alison to be with groups of people and that this may have 'put him off asking for help' out of concern for her.

Peter said that it was hard to get any support before the NDIS. After Alison's first hospital stay 20 years ago, they had an occupational therapist visit and arrange for some railings to be installed. They tried to access rehabilitation services after Alison was discharged from hospital and were told that the service was full. This happened again when Alison had subsequent attacks. Peter said 'I think it's assumed that you [the carer] will do everything. You don't really have a choice. You just have to get on with it. You're battling because the [health] system is overflowing.'

Over the past eight years, they did get some MS rehabilitation services but 'the support fizzled out after a while'. Peter said there was never any mention from this service, the GP, or the neurologist Alison was seeing about supports for him as a carer for Alison. He said, 'Maybe they thought we had everything under control, and we were doing ok.'

Around 18 months ago, Peter was speaking to a neurologist who lives in their street. The neurologist has a special interest in MS and knew Alison has the condition, so he suggested they apply for access to the NDIS. This was a 'chance conversation' as the neurologist was not treating Alison at that time. It was also timely as Alison was 63 and would not be able to access the NDIS once she turned 65. This was the first time anyone had suggested the NDIS to Alison and Peter. Peter describes the neurologist as 'a lucky find' and the only reason they are now getting support.

After Alison's access request was submitted, they did not receive a reply for over a month. Peter contacted the NDIA and was advised the access request paperwork had been lost. The NDIA checked their records, located the application, reviewed the request, and approved access for Alison in February 2020.

Around the same time, Peter contacted the MS Society and they gave him a lot of information and support. An advocate from the organisation went to the NDIS planning meeting with them. Peter said, 'If the advocate wasn't there, we would have missed out on so much. We just didn't know what was available and what to ask for.' Peter said they see many other people who are in a worse position than they are, and this 'makes them reluctant to ask for much'.

Peter said that because they had the presence of the advocate at the planning meeting, Alison's NDIS package now includes funding for some help with housework, companionship and social support, some equipment so Alison can be more independent at home, and physiotherapy and exercise physiology. Having therapy included was a great relief to Peter and Alison; they were worried about how they could afford to pay for it in the future.

Peter cannot recall if he was asked about his needs as a carer during the NDIS planning process. He said, 'If I have more help, it means I can work more and be productive.' Peter expressed the desire to continue working in his business as long as he can.

When asked what improvements are needed to the system, Peter talked about changes that are required so that people can access basic support like Centrelink. He described how he contacted Centrelink to apply for the Carers Allowance. He said, 'It was a nightmare. After going into the Centrelink office, I was told to phone the call centre. I sat on the phone waiting for hours. When I spoke with someone, they mailed some forms to me. It was just before Christmas, and I was only given 10 days to complete the forms and get reports from Alison's doctor and specialist. It was not possible to do in 10 days at any time of year, let alone just before Christmas. I phoned Centrelink and asked if I could have an extension of time. I was told this wasn't possible and I would have to start the application process again. I gave up.' Peter said, 'You're put through such a process, it's almost as though they're trying to get out of helping you.'

Peter also talked about the importance of having access to the right information at the right time. Peter said people with  chronic illness need 'access to a consistent advocate who knows the system'. He said, 'If you Google "NDIS", hundreds of results come up. It's too many to go through.' Peter said that Alison's NDIS plan includes support coordination for the first 12 months, but they are unclear on what the Support Coordinator will or can do, as they do not know the process.

Peter describes how the NDIS planner and Local Area Coordinator that met with them were both new to their role and Alison was 'their first participant'. He said, 'I rely on them to guide us. If they don't know what to do it's just another thing for us to deal with. When they both said we were their first (NDIS participant) it wasn't what I needed to hear.'

## Case Study 5 – Laura and Michelle

Laura, a 70-year-old woman, is the primary carer for her daughter, Michelle, who has cystic fibrosis (CF). Michelle is 50-years-old and lives with her husband and teenage son, who are also her carers. Laura has been caring for Michelle since her daughter was born. Laura lives near Michelle's family home and usually provides 5–10 hours of support each week, although this increases when Michelle is unwell due to CF.

Laura said when Michelle was a child, they accessed some CF services but 'wanted Michelle to have a very active and healthy life and not see herself as sick'. Laura built a strong informal network of other mothers of children with CF. Laura said this group was helpful because the members could share strategies and information about CF.

Michelle said the most important formal support for her is chest clearance (or assisted airway clearance). She had been getting daily chest clearance from the Homecare Service of NSW since she was 19-years-old. Before the NDIS was introduced, Homecare Service was transferred to Australian Unity, and she continued to get chest clearance through them.

> Michelle was told 'CF is a condition you will die from because of damage to your lungs. That's a health condition, not a disability.' Michelle commented that at this point in the application process, she had 'a reasonable baseline of good mental health'. Michelle said she 'wonders how a conversation like this might affect someone with poor mental health.'

When the NDIS was introduced, Michelle put in an access request. She included 'letters from her CF specialist, GP, physiotherapist and social worker'. Michelle's first application was declined on the basis that 'mainstream support options would be able to meet her needs and CF is not considered a lifelong condition'. Michelle said, 'Someone at the NDIS told me I could access mainstream health services. This just isn't an option for daily chest clearance. This service just isn't available. CF is a genetic condition, which makes it lifelong.'

Michelle requested a review of the decision and included additional documentation, including carer statements from Laura, and her husband and son. The initial decision was upheld; this meant Michelle was not an approved participant of the NDIS.

Michelle said when she spoke with someone at the NDIA about this second decision, she asked why people with other degenerative conditions (such as MS) or other genetic conditions (such as down syndrome) were covered under the scheme, but CF was not. Michelle was told 'CF is a condition you will die from because of damage to your lungs. That's a health condition, not a disability.' Michelle commented that at this point in the application process, she had 'a reasonable baseline of good mental health'. Michelle said she 'wonders how a conversation like this might affect someone with poor mental health'.

Michelle made an application to the Administrative Appeals Tribunal (AAT). During the AAT process, the solicitor engaged by the NDIA stated they intended to subpoena all of Michelle's medical records from the time she turned six-years-old (when she was diagnosed with CF) until the time of her NDIS application. Michelle commented on the significant cost this would have incurred and the invasion of her privacy. She said, 'I asked [someone at the NDIA] what would happen to the copies of my medical records once they were subpoenaed and they said, they didn't know. I asked what would happen if I had a medical episode while my records were being copied and possibly unavailable. The person said, "This would be good because it would give us up-to-date information on your condition." Essentially they were saying it would be good if I had an episode of bad health because it would give the NDIA more information.' Before the matter was determined by the AAT, a settlement was reached. This meant Michelle could access the NDIS and receive funded support. Michelle said that while this was a good outcome for her, it meant others with CF could not refer to her case as an example.

Laura said, 'During the appeal process, Michelle was spending around two days each week collecting evidence for her appeal, writing letters, and contacting public officials to advocate for herself and others with CF to access the NDIS.' She also said, 'During this time I did a lot more in my caring role. I could see how much stress Michelle was under, so I did a lot of cooking, cleaning, taking her son where he needed to go, to take some pressure off Michelle.'

In order to maintain her job, Michelle needs to stay on top of her health. She said, 'I already operate at 50% lung capacity so I need to do everything I can to maintain that level. Daily chest clearance is essential for that.' Laura said, 'I told Michelle I would do the chest clearance for her every day if it came to that.' However, she also said, 'Physically, I couldn't do the chest clearance for an hour, it's just too tiring. If I had to do it, I couldn't go away, and it would definitely limit the other things I could do in my own life.'

Laura also commented on whether people with disability should be expected to rely on family for essential support. She said, 'Parents shouldn't be doing chest clearance for their adult children. [The person with CF] should be able to be independent, to make their own decisions about their treatment and support. When family provide things like chest clearance, it can be detrimental to those relationships. It causes resentment on both sides. It's an invasion on that relationship.'

In relation to accessing the NDIS, Laura said,

As a carer, and for Michelle it was a very helpless position to be in. CF is hard enough as it is. Watching Michelle go through such a difficult application and appeal process was really difficult. If she hadn't got the NDIS, it would have been disastrous.

Laura said, 'A lot of people don't have the energy [for a process like that]. When you have CF, you are fighting to stay well.'

When asked about the barriers for carers and people with disability, Laura said, 'English is our first language, we are educated and reasonably well off. Michelle isn't afraid of forms or fighting the system. What about people who aren't in that situation?' Laura commented that in her experience 'Most families are used to doing things for themselves. They don't look for help. They just get on with it.' Laura also said she is unlikely to seek out formal supports because she worries there aren't enough to go around and she doesn't want to take support away from another carer who may need it more.

Michelle commented that because life expectancy for people with CF has increased since she was a child, more people with CF are living into adulthood, getting married and having children. This means services are needed to support people so they can stay healthy and have good quality of life. Michelle said, 'So many people with CF and their families don't follow through [after NDIS access is declined]; it's just too hard and too tiring.' Michelle said 'it felt as though the NDIS was set up for me not to get in. Not getting the NDIS would have placed enormous pressure on my marriage and my other family relationships.'

## Case Study 6 – Lisa

Lisa is a 45-year-old woman with cystic fibrosis (CF). She also has other health conditions because of CF. She cannot drive at night due to diabetic retinopathy and she cannot raise her arms above shoulder height because of tendinitis and a rotator cuff condition. She also experiences mental health issues. Lisa lives alone and is supported by Suzanna who is in her late 70s. Suzanna is the mother of Lisa's ex-partner. Lisa and her ex have not been in a relationship for the past 13 years, but Suzanna has continued to be Lisa's carer. Suzanna and Lisa have a close relationship. Suzanna comes every fortnight to help with cleaning, changing bed sheets, and cooking. Lisa said, 'Suzanna is not always available and it's not fair to rely on her. She has two grandchildren and is getting older. I worry about what would happen if the friendship breaks down. Having to rely on her as a carer is a burden on our friendship.'

Lisa has recently been granted access to the NDIS after a year-long process. Lisa's first access request and subsequent appeal were both rejected. She said at that time, 'the person I spoke to from the NDIS said "you have a bit of help (from Suzanna). Why don't you try and apply again when you are sicker?

Lisa said, 'I live alone so there is no-one to help with cleaning or shopping. I'm not able to work, so I can't afford private help. Every service I contacted said they can only help people with either aged care funding or the NDIS. In the past you could get Homecare which was discounted. I didn't use a lot of services in the past because I was quite independent.'

Lisa has recently been granted access to the NDIS after a year-long process. Lisa's first access request and subsequent appeal were both rejected. She said at that time, 'The person I spoke to from the NDIS said "you have a bit of help [from Suzanna]. Why don't you try and apply again when you are sicker? You're not so bad yet."' Lisa said, 'I am trying to prevent my health from getting worse so I can stay independent. If I end up in hospital, that's expensive for the system.'

Lisa took the matter to the Administrative Appeals Tribunal (AAT) with the support of a pro bono solicitor. Lisa said she could not have gone through the process otherwise as 'it would have been too stressful'. Lisa said the pro bono solicitor did all of the submissions and her GP was interviewed as part of the AAT process. Lisa said her GP was a very strong advocate and gave evidence that she has less than 50% lung function, which is likely to decline over time.

Lisa said, ‘The NDIS access process involves lots of timeframes to meet. If you can’t get the paperwork in on time, you have to start again. It’s all very disheartening and it’s not fair to say that CF is not a disability. It affects so many aspects of your functioning in daily life.’

Lisa is still waiting to see what supports have been approved as part of her NDIS plan. She said being on a low income means that paying for private support and even shopping delivery is too expensive. During COVID-19 it is ‘risky for her to go out shopping but it’s also risky for Suzanna because of her age’. Lisa said she has no choice until her NDIS services start. Lisa said she does chest clearance herself with the help of some equipment. She said the Local Area Coordinator told her, it’s highly unlikely she’ll get daily support for chest clearance. Lisa has asked for her plan to include support with chest clearance during times that she is unwell.

# Endnotes

i Over several years HACC funding was essentially split into two funding pools: the Commonwealth Home Support Programme (CHSP) for people over 65 years of age and the Community Care Supports Program (CCSP), funded by the NSW government to provide HACC-type supports to people with disability under 65 years of age. See Section 3 of this report for details of these policy changes.

ii From here, the term carers is used to refer to carers of people aged 0–64 years.

iii The *Support Coordination Program for Older Parent Carers*, provided by Carers NSW until 2017, for example, offered succession planning, case management, workshops and peer support specifically for carers. The SCP service aim from the Support Coordination Guidelines states, 'The primary focus of these funds is to provide support for the carer' (8).

iv 'Formal assistance' refers to assistance received from people employed to provide support, e.g., support workers, nurses, speech therapists, physiotherapists, psychologists, cleaners, gardeners, accountants, and teachers.

v 'Informal assistance' refers to unpaid assistance received from family and friend carers.

vi A primary carer is defined by the ABS as a person aged 15 years and over who provides the most informal assistance to a person with disability for the core activities of mobility, self-care, and communication.

vii In NSW, ADHC respite funding in 2017 allowed for a cap of $8000 for non-residential respite. Support Coordination Carer Assistance packages were $5000.

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