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15 October 2020

National Disability Strategy Governance and Engagement Section
GPO Box 9820
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On behalf of the National Carer Network, Carers NSW welcomes the opportunity to respond to the Department of Social Services National Disability Strategy Position paper. This submission has been developed by Carers NSW in collaboration with the National Carer Network.

The National Carer Network consists of Carers Australia and the Carer Associations in each state and territory. Our shared vision is an Australia that values and supports all carers. The National Carer Network defines a carer as any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our collective vision is an Australia that values and supports all carers.

This submission focuses on the importance of carer recognition and inclusion in the National Disability Strategy, recognising "the vital role carers play in providing care, support and assistance to people with disability in order to reach their full potential."[1] It also highlights the importance of monitoring and reporting on carer outcomes to ensure the effectiveness of the strategy not only for people with disability but also carers of people with disability. The National Carer Network believes that the success of the Strategy is dependent on its ability to identify and address the needs of carers alongside those of people with disability.

The National Carer Network also calls for the development of a whole of government National Carer Strategy to complement the National Disability Strategy and other related frameworks, and to support the delivery of the new national Carer Gateway service system.[2]

Thank you for accepting this submission. For further information, please contact Sarah Judd-Lam, Manager, Policy and Research, Carers NSW at sarahj@carersnsw.org.au or on (02) 9280 4744.

Yours sincerely,

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CEO
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[1] DSS (2020) *National Disability Strategy Position Paper*, p.2
[2] Carers Australia (2020) *Carers Australia submission: Pre-Budget 2020,* August 2020, available online at: https://www.carersaustralia.com.au/pre-budget-submission-invisible-army-of-unpaid-carers-need-improved-recognition-and-support/

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Submission by Carers NSW on behalf of the National Carer Network:

National Disability Strategy Position paper

15 October 2020

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Introduction

The National Carer Network believes in the importance of autonomy and self-determination for people with disability and is supportive of policy and practice that facilitates their independence and meaningful participation in community life. The review of the National Disability Strategy (the Strategy) presents a valuable opportunity for the state and territory Carer Associations to highlight the crucial role of family and friend carers in the lives of people with disability and ensure carers' interests and outcomes are adequately reflected.

The National Carer Network recognises that not all people with disability receive informal support or would identify with having a 'carer'. However, family members and friends are important in the lives of all Australians, and the Australian Bureau of Statistics (ABS) reports that the majority of Australians with a reported disability who need assistance receive at least some of that assistance from a family member or friend; in many cases, on a daily basis.[3] More than one third (37.4%) of primary carers also have a reported disability themselves, more than twice the rate of non-carers (15.3%).[4]

The value of carers in the lives of people with disability is noted early on in the National Disability Strategy Position Paper (the Paper),[5] reflecting an understanding that the care, support and assistance provided by family members and friends plays a critical role in improving the wellbeing, engagement and self-determination of people with disability. In addition to providing direct personal care and other practical and emotional support, carers are often active in supporting people with disability to navigate, access and coordinate mainstream and specialised services and participation in the community and in education and employment. This means that barriers to access affecting people with disability and issues with the quality or safety of services often affect carers as well as people with disability, and carers are often key advocates in having these issues addressed.

According to the ABS there are approximately 2.65 million carers across Australia, including 861,600 primary carers.[6] For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment and community activities. It has been estimated that value of informal care provided by family and friend carers has risen to $72 billion each year,[7] with Deloitte Access Economics projecting it would cost the Australian Government just under $1.5 billion per week to replace.

The recent outbreak of the Coronavirus (COVID-19) in Australia has further highlighted the important role that carers play in supporting people with disability, especially when formal services are compromised or withdrawn. As heard at the Disability Royal Commission Coronavirus hearing, many carers have taken on additional caring tasks in place of suspended or reduced specialist and mainstream services and supports during the pandemic to support the wellbeing and participation of people with disability during the pandemic.[8] Indeed, international research indicates that existing caring roles have intensified overall, and many people have become carers for the first time, during COVID-19.[9]

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[3] Australian Bureau of Statistics (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset, available online at: www.abs.gov.au

[4] Ibid.

[5] DSS (2020) *National Disability Strategy Position Paper*, p.2

[6] Australian Bureau of Statistics (2019) *Disability, Ageing and Carers, Australia: Summary of findings, 2018,* New South Wales Tables, Canberra.

[7] Carers NSW analysis based on national findings from Deloitte Access Economics (2020) *The economic value of informal care in Australia in 2020*.

[8] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) *Transcript Day 1 – Public hearing 5, Sydney*, available online at: https://disability.royalcommission.gov.au/publications/transcript-day-1-public-hearing-5-sydney.

[9] Carers NSW (2020) *COVID-19 and carers: A review of the evidence*, available online athttp://www.carersnsw.org.au/policy/changing-systems.

Recognising and supporting the important role of carers in the lives of people with disability and in facilitating the inclusion of people with disability will be critical to the ongoing success of the Strategy, as this submission explores further.

Carer recognition and inclusion

Recommendations:

- Include the definition of a carer as per the *Carer Recognition Act 2010* in the Strategy
- Align the Strategy with state, territory and Commonwealth carer recognition legislation and state and territory carer strategies
- Genuinely include carers in all areas of the Strategy, including the vision, objectives, guiding principles, outcomes, engagement, reporting and evaluation
- Develop a complementary whole of government National Carer Strategy

The National Carer Network commends the Department on its acknowledgement and recognition of carers throughout the Position Paper[10] and the introduction of a guiding principle focusing on carers and supporters in the Strategy. However, we believe more attention needs to be paid to the integration of carer recognition throughout the Strategy. It is particularly important that carers not only be included in principle, but also in practice, with genuine efforts to promote carer recognition and support being reflected across key areas.

The findings of the first round of consultation on the Strategy indicate that there is general support from stakeholders for greater recognition and inclusion of carers in the new Strategy. The consultation found that almost two thirds of participants rated support for carers as a severe or major issue[11] and almost all participants (90%) felt that greater support for families and carers should be a high or essential government priority, the highest rated priority by consultation participants.[12] The recently conducted 2020 National Carer Survey found that half of all respondents disagreed that their caring role was recognised by governments, and that the majority of carers of NDIS participants were *not* asked about their own needs during the planning process.[13]

The National Carer Network supports the suggestion raised in the first round of consultations that a National Carer Strategy should be developed under the National Disability Agreement (NDA) to sit alongside the new Strategy,[14] enabling carers to have an enhanced quality of life and participate as valued members of the community, as per the objective outlined in the NDA.[15] The call for a National Carer Strategy was recently renewed in Carers Australia's 2020 Pre-Budget Submission.[16]

While a National Carer Strategy did exist from 2011-2014, the lack of continuity post-2014 has resulted in reduced emphasis on the importance of a whole-of-government and whole-of-society commitment to supporting carers' interests, even amid the major reforms to the carer support sector occurring during this period. Regardless of whether or not a new National Carer Strategy proceeds, the National Carer

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[10] Department of Social Services (2020a) *National Disability Strategy: Position paper*, available online at https://engage.dss.gov.au/wp-content/uploads/2020/07/national-disability-strategy-position-paper-accessible-pdf.pdf

[11] DSS (2019a) *Right to Opportunity: Consultation report to help shape the next national disability strategy - Full Report,* available online at: https://www.dss.gov.au/sites/default/files/documents/12_2019/ndsbeyond2020-fullreport-161219_0.pdf.

[12] DSS (2019b) *Right to opportunity: Consultation report to help shape the next national disability strategy – Appendices*, available online at: https://www.dss.gov.au/sites/default/files/documents/12_2019/ndsbeyond2020_appendicesatt_final_11_december.pdf.

[13] Carers NSW (2020) *2020 National Carer Survey: Summary report*, not yet published at the time of writing.

[14] DSS (2019a).

[15] Council of Australian Governments (CoAG) (2009) *National Disability Agreement*, available online at http://www.federalfinancialrelations.gov.au/content/npa/national_agreements/national-disability-agreement.pdf

[16] Carers Australia (2020).

Network believes that the Disability Strategy should explicitly support the inclusion of carers of people with disability in its objectives and implementation.

A key step to improving carer inclusion in the Strategy would be referring to carers in the vision statement, a departure from the last Strategy. Furthermore, the Strategy must increase inclusion of carers by creating greater provisions, responsibilities and obligations regarding supports for carers, as well as look to identify and address the service gaps that are currently being filled by carers. Reducing strain on carers and providing adequate carer supports will ensure that carer health and wellbeing is maintained and that carers can continue to provide care and support more sustainably to people with disability.

It is also important that the Strategy align with and complement any future National Carer Strategy, the Commonwealth *Carer Recognition Act 2010* and equivalent carer strategies and carer recognition legislation at state and territory level in order to strengthen existing carer policy coordination and clarify which level of government has which responsibilities, enabling optimal outcomes for carers and the people with disability they care for.

Clarifying roles and responsibilities

Recommendations:

- Clarify responsibility for the service mapping of the disability sector to ensure that service gaps are identified and minimise service duplication
- Identify, in consultation with people with disability, carers and the sector, the minimum level of support that should be available to people with disability who are ineligible for the NDIS and their carers, and specify who is responsible for providing this support
- Clarify service system boundaries and encourage better integration between levels of government to ensure holistic, streamlined support for people with disability and carers
- Clarify processes to ensure adequate services and supports are available in complex situations
- Clarify the interface between the NDIS and Carer Gateway
- Clarify who is responsible for funding disability advocacy and service navigation support
- Make information about the responsibilities of different levels of government is clearly communicated to people with disability and their carers

The National Carer Network supports the clarification within the Strategy of the roles and responsibilities of Commonwealth, state and territory and local governments in relation to people with disability and their carers. Since the development of the NDA and the previous NDS, there has been significant reform in the disability sector. Clearly delineating the expectations of different levels of government in addressing the ongoing support needs of people with disability and their carers, across settings, sectors and jurisdictions will ensure that they have the same rights, choices and opportunities as other Australians.

The introduction of the National Disability Insurance Scheme (NDIS) was a monumental accomplishment for people with disability, their families and carers. However, by shifting the bulk of responsibility for disability policy and service provision from the state and territory governments to the

Commonwealth Government, the rollout of the NDIS has created confusion and stalemate in a number of areas where it is not clear which level of government should be responsible for ensuring supports are available and accessible.

The recent COVID-19 pandemic has only highlighted issues created by the lack of clarity around Commonwealth, state and territory government responsibilities, with vastly different responses across different jurisdictions and considerable confusion and contradiction between Commonwealth Government directions and those provided by Premiers and Chief Ministers. The recent introduction of the Disability Gateway, which is currently out to tender, has further raised questions about the ongoing expectations of state and territory governments to provide direct services as well as service navigation supports to people with disability.

Responsibility for supporting people with disability ineligible for the NDIS

Of the approximate 4.4 million people with disability in Australia,[17] it is estimated that only 475,000 will be eligible to receive supports through the NDIS.[18] With all states and territories now transitioning or fully transitioned to the NDIS, the Strategy must address responsibility for supports for people with disability who are not eligible for the NDIS. While some states and territories have put plans in place or extended existing arrangements to ensure that people with disability outside of the NDIS are adequately supported to access both mainstream and specialist disability services, in other jurisdictions such as NSW, residual resourcing to ensure the inclusion and support of people with disability is limited.

As the Disability Royal Commission has highlighted, many mainstream service systems which are within the remit of state and territory governments, such as health, education and housing, continue to exclude and discriminate against people with disability and their carers. For example, housing has been highlighted as a key issue for people with disability and their carers in WA, where a lack of information and services to assist people with disability in identifying housing options and a shortage of accessible private rental properties indicate the need for additional State Government action to increase the inclusiveness of mainstream services.[19]

In NSW, despite an anticipated 50% increase in students with disability accessing public schools, planning for inclusion remains inadequate even for current school populations.[20] Further, in a recent review of before and after school care (BASC) programs in NSW, disability inclusion was not a stated priority, despite the difficulty many parents of children with disability report in accessing these services, and the subsequent implications for children's outcomes and parents' capacity to remain in paid employment.[21]

The additional pressures and disruptions caused by the COVID-19 pandemic have only exacerbated the issues people with disability have experienced in accessing appropriate education and housing, and as in other areas where formal services fall short of need, carers have in many cases stepped into the gap, often to an unsustainable extent.

Inconsistency between states and territories in the delivery of specialist disability and community care services to people with disability who are not eligible for the NDIS has also been continually highlighted

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[17] Australian Bureau of Statistics (2019) *Disability, Ageing and Carers, Australia: Summary of findings, 2018,* New South Wales Tables, Canberra.

[18] Productivity Commission (2019) *Review of the National Disability Agreement: Productivity Commission Study Report*, available online at: https://www.pc.gov.au/inquiries/completed/disability-agreement/report/disability-agreement.pdf.

[19] Carers WA and Foundation Housing (2020) *Experiences of Western Australians with disability finding a home*, June 2020, available online at: https://www.carerswa.asn.au/wp-content/uploads/2020/07/Accessing-a-Home-Report-June-2020-Final.pdf

[20] Baker, J. (2020) 'Schools must prepare for 50 per cent rise in students with disabilities: report', *Sydney Morning Herald*, 2 September 2020, available online at: https://www.smh.com.au/national/nsw/schools-must-prepare-for-50-per-cent-rise-in-students-with-disabilities-report-20200902-p55rrm.html

[21] Carers NSW (2019) *Carers NSW submission to the NSW Department of Education on before and after school care programs,* 2 August 2019, available online at: http://www.carersnsw.org.au/page/884

especially in NSW, where, in the transition to the NDIS, a number of State-funded disability support programs and carer support programs were rolled into the NDIS, but not replicated within it. Other states, however, such as Victoria continue to provide ongoing direct supports to people with disability outside the NDIS.[22] While NDIS Local Area Coordinators (LACs) were intended to provide ongoing support and referral to people with disability who were not eligible for the NDIS, in many areas, the significant volume of NDIS related planning and plan implementation work has taken priority, with few resources for LACs to support people with disability outside of the NDIS.

Federal Ministers and agencies[23] continue to argue that state and territory governments are responsible for providing continuity of support to people outside of the NDIS, however while state and territory governments differ in their response to this expectation, direct support for large numbers of Australians with disability and their carers varies widely. This disparity will only become more apparent as the Disability Gateway project commences, as its expectation of providing a central referral point to disability information and support may be frustrated by limited referral options in certain jurisdictions. A parallel challenge is the limited information that exists about the support arrangements and support needs of people with disability and their carers who are outside of the NDIS, which will make it difficult to identify service gaps and support needs.

The National Carer Network recommends that the new Strategy clearly delineate the expectations of different levels of government in addressing the ongoing support needs of people with disability not eligible for the NDIS, both in relation to accessing specialist disability and community care supports where required, and in relation to benefiting from more accessible, better resourced inclusive mainstream service systems. A minimum level of support should be available to people with disability and their carers across Australia, with quality data collected on the delivery and outcomes of this support to ensure that needs are being understood and met. Ensuring that people with disability can access specialised support and assistance to access mainstream services will reduce the strain on carers who are currently filling significant service gaps.

Intersecting service systems

Many carers of people with disability receiving supports through the NDIS have reported significant difficulties obtaining an acceptable outcome where support needs arise at the interface of two different service systems, such as health and disability services, especially where one system (such as health services) is predominantly State managed and funded and the other (in this case, disability services) is predominantly managed and funded by the Commonwealth. A number of these cases have been tested in the Administrative Appeals Tribunal, for example, in NSW the coverage of people living with cystic fibrosis under the NDIS has been a significant issue, with NSW Health challenging their exclusion from eligibility for the Scheme. The recent Review of the *NDIS Act* (the Tune Review)[24] emphasised the need to address these kinds of interface issues by better defining the responsibilities of different levels and parts of government to ensure holistic, streamlined support for people with disability.

The National Carer Network acknowledges the Disability Reform Committee's (DRC) ongoing work in clarifying the boundaries between the NDIS and other service systems, including the health service system, and the existence of the Applied Principles and Tables of Support (APToS). However, carers report ongoing difficulties in sustainably supporting the people they care for when they are required to advocate so heavily to get the formal services they need, while not receiving any service in the

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[22] Vic Health (n.d.) *HACC PYP services*, available online at: https://www2.health.vic.gov.au/ageing-and-aged-care/home-and-community-care/hacc-program-for-younger-people/hacc-services

[23] e.g. Commonwealth of Australia. House of Representatives (2020), *Questions without notice, COVID-19: Disability* (Official Hansard), available online at: https://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/b8197f17-5287-4edd-8f7f-5577701ad7c3/0157/hansard_frag.pdf;fileType=application%2Fpdf

[24] DSS (2019) *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee*, available online at: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

meantime. While the Government has supported the Tune Review's recommendation to clarify service boundaries,[25] concerns remain that these issues will continue. Furthermore, given the recent dissolution of the DRC, to be replaced with a disability ministers' forum,[26] which's form and role is yet to be decided, it is not clear how and when these issues will be addressed.

The National Carer Network believes the Strategy should clearly identify and outline responsibility and accountability for different departments to work together effectively in order to clarify boundaries between the NDIS and other service systems and ensure streamlined holistic support for people with disability and their carers. Furthermore, there should be clear guidance for people with disability and their carers around accountability where service systems cannot come to an agreement on responsibility to ensure that people with disability can access essential supports and that carers are not placed under additional strain to engage in significant advocacy or fill service gaps.

Access to carer-specific supports

With many carer support programs rolled into the NDIS, carers have also faced increasing difficulty accessing support to continue in their caring role. Inconsistent residual disability supports and investment in carer supports across states and territories have meant that many carers of those ineligible for the NDIS have been unable to access carer focused supports. Furthermore, despite many carer support programs being rolled into the NDIS, the term 'respite' was intentionally omitted from NDIS language until it was recently reintroduced to the Price Guide in late 2019. Carers of those who are receiving supports through the NDIS have reported difficulty accessing the support they need through the Scheme, including respite, to continue in their caring role and some have reported that the expectation on them to provide care has resulted in reduced funding available for formal supports for their care recipient.

While the new Carer Gateway will provide some support to carers through counselling, coaching, carer directed supports and emergency respite, it is intended that established service systems, including the disability service system, will continue to provide ongoing support for carers, including planned breaks from the caring role. The AAT, in a number of hearings related accessing carer supports through the NDIS[27] and the Tune Review[28] have highlighted the need for better recognition and support for carers through the NDIS as this is in the interest of the person with disability who is likely to have better outcomes if their carer is better supported. The National Carer Network believes that the Strategy should clearly outline the responsibility of all levels of government in providing carer-specific supports to ensure that carers can access the support that they need, and continue in their caring role.

Funding disability advocacy services

With the rollout of the NDIS across Australia, people with disability and their carers are not only facing complex new systems with a reduction in certain types of support; many are also dealing with multiple other mainstream service systems which they require support to navigate effectively including, but not limited to, health, education, justice, accommodation and employment. Additionally, disability advocacy services have witnessed an increased demand from NDIS participants, families and carers whose plans

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[25] Australian Government (2020) *Australian Government response to the 2019 Review of the National Disability Insurance Scheme Act 2013 report*, available online at: https://www.dss.gov.au/sites/default/files/documents/08_2020/australian-government-response-tune-review-28-august-2020-release.pdf

[26] DSS (2020) *Statement - Disability Ministers Meeting 24 July 2020,* available online at: https://www.dss.gov.au/sites/default/files/documents/07_2020/statement_-_disability_ministers_meeting_24_july_2020.pdf

[27] Carers Australia (2018), *Review of NDIS respite care decisions by the Administrative Appeals Tribunal – A resource for carers*, available online at: https://www.carersaustralia.com.au/files/download/?id=1919

[28] DSS (2019) *Review of the National Disability Insurance Scheme Act 2013: Removing red tape and implementing the NDIS Participant Service Guarantee,* available online at: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

do not meet their needs.[29] The reduction in case management support across the sector and increased pressure on the disability advocacy sector to support with complex legalistic NDIS issues has placed additional strain on carers to provide greater support with administrative and advocacy tasks to uphold the rights of people with disability that they care for. In some states and territories, such as NSW, state funding for disability advocacy services has been eroded due to the mistaken assumption that the NDIS and National Disability Advocacy Program (NDAP) will address all advocacy needs.

The National Carer Network acknowledges that the Commonwealth Government has made a commitment to the funding the NDAP, NDIS Appeal Support program and Disability Representative Organisations,[30] however, these commitments alone are not equivalent to the previous funding levels received by disability advocacy services in Australia. Furthermore, many of the service systems in which people with disability and their carers need assistance with advocacy fall within state and territory responsibility. In a complex service environment with ongoing change and jurisdictional complexity, the funding shortfall for disability advocacy will continue to grow.

The Productivity Commission's 2017 *NDIS Costs* report recommended that states and territories that had reduced or ceased disability advocacy funding should restore it and increase data collection and evaluation, citing the ongoing importance of independent disability advocacy.[31] The Joint Standing Committee on the NDIS has further highlighted the importance of disability advocacy, noting that all levels of government have a responsibility to support disability advocacy.[32] The Commonwealth Government has in turn recommended ongoing investment in disability advocacy from the states and territories to ensure that people with disability and their carers can resolve issues within state-run service systems.[33]

The National Carer Network believes that the Strategy should highlight the role of state and territory governments in the ongoing provision of disability advocacy support at both individual and systemic levels and encourage further investigation of the unmet need for disability advocacy in Australia. Ongoing and increased investment in disability advocacy will ensure that all people with disability have fair and equitable access to services and supports and can be supported against potential injustices, whilst reducing strain on carers who would otherwise be required to fill this advocacy gap.

Accessible guidance on responsibilities

Current publicly available information on the roles and responsibilities of different levels of government in regards to supports for people with disability who are not eligible for the NDIS is limited, vague and legalistic. For carers who are supporting people with disability to navigate complex, disjointed mainstream services and supports that are not adequately equipped to support people, this often means that it is difficult to determine who is responsible for providing the support needed. Furthermore, complicated redress pathways create another level of complexity that people with disability and their carers must navigate to access the appropriate support.

The Carers NSW 2018 Carer Survey found that since the rollout of the NDIS in 2016, over two thirds of respondents caring for an NDIS participant in NSW and almost half of respondents caring for a person

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[29] Victorian Disability Advocacy Futures plan 2018-2020

[30] Parliament of Australia (2019) *Joint Standing Committee on the National Disability Insurance Scheme: Progress report*, March 2019, available online at: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS/~/media/Committees/ndis_ctte/General_NDIS/report.pdf.

[31] Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs*, Study Report, available online at: https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs-overview.pdf.

[32] Parliament of Australia (2019), *Joint Standing Committee on the National Disability Insurance Scheme: Progress report*, March 2019, available online at: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_NDIS/~/media/Committees/ndis_ctte/General_NDIS/report.pdf.

[33] Ibid.

under the age of 65 who was not accessing the NDIS had experienced an increase in time spent organising supports for their care recipient.[34] Further, many carers have reported to the state and territory Carer Associations that the additional strain associated with navigating disability reforms has placed immense strain on their health and wellbeing, in some cases to such an extent that it has disrupted caring arrangements.

Initial results from the 2020 National Carer Survey indicate that only a minority of carers of NDIS participants (approximately one in three) were provided with the information they needed or said NDIS supports were easy to organise, and even fewer (approximately one in four) said the supports provided by the NDIS met their needs as a carer.

The National Carer Network believes that the clarification of responsibilities between governments and service systems should be provided in diverse, universally accessible formats, including paper based and digital resources in plain English and Easy Read, to ensure that they can be effectively understood by all people with disability and their carers. Furthermore, there should be greater clarity around processes where Governments, agencies or organisations cannot agree on which party is responsible to ensure that people with disability and their carers are not disadvantaged by ongoing disagreements between these parties.

Measuring outcomes and reporting

Recommendations:

- Include carer specific outcomes in all data collection and reporting
- Provide regular public reporting on progress and outcomes through a biennial published report that is accessible for people with disability and their carers
- Clarify where is data coming from and how more data will be collected for reporting, especially for the majority of people with disability who are not NDIS eligible
- Review existing data collection methods to determine where greater depth of information could be collected
- Increase data sharing between agencies to better understand and address interface issues and strengthen reporting
- Include a carer engagement plan in the Strategy
- Ensure that any commitment from governments to undertake policy and program evaluations is carer inclusive

Many people with disability are supported to increase or optimise their participation in the community by their carer or carers. A well-rounded Strategy should acknowledge carers in this role and look to create accountability for governments to adequately support carers as this also supports the outcomes of the people with disability that they care for. The National Carer Network believes that including carer focused outcomes measures in the Strategy is essential to ensuring that carers are a focus of the Strategy and that governments and non-government organisations are held accountable for improving the inclusion and participation of carers. This should include the development of benchmarks for best practice that can be monitored, evaluated and reported against at national level, and compared with data from other service systems such as the Carer Gateway and My Aged Care.

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[34] Carers NSW 2018 Carer Survey, unpublished data.

In order to ensure accountability for all levels of government and the non-government sector in improving outcomes, the National Carer Network supports the proposal of regular reporting on outcomes in biennial progress reports.[35] However, we have concerns that current data collection on the range of life areas covered in the strategy is limited and may not enable two yearly reporting on the progress of the Strategy.

Current national surveys that collect data on people with disability and their carers are infrequent and limited in their depth of information. The Survey of Disability, Ageing and Carers (SDAC), while focusing on people with disability and their carers is conducted every three years and the Census is conducted on a 5 yearly basis and does not captured nuanced issues for people with disability or carers. Furthermore, the cessation of the Disability Services Minimum Data Set (2019) has seen a reduction in the amount of data collected about the service use of people with disability outside of the NDIS and the NDIS Participant and Family and Carer outcome measures do not adequately capture enough data to report on all aspects of the Strategy.

Limited data sharing between levels of government and different government agencies creates further difficulties in identifying and monitoring intersectional issues, such as older people with disability. Recent comments made by the minister for the NDIS, the Hon. Stuart Robert MP.,[36] in regards to the limited collection or coordination of state and territory disability information at a federal level during COVID-19 raises greater concerns about the limited availability of nationally collected and consistent data on people with disability, especially those who are not eligible for the NDIS.

The National Carer Network supports better overall collection, sharing, monitoring and reporting on data, however believes that this should also include improved collection and reporting of carer data to enable more regular and accurate reporting on the Strategy. As users, co-users or significant stakeholders impacted by the development and delivery of disability-specific and mainstream services and supports, carers should be represented and considered in data collection. The Strategy should encourage the collection of carer data in all relevant data sets across Australia (including those held by the Department of Social Services, National Disability Insurance Agency, Services Australia and state and territory departments responsible for overseeing disability policy and services) as best practice to increase the depth of carer data available. Without better understanding of the number, diversity and experiences of carers, it is not possible to monitor the effectiveness of the Strategy in optimising outcomes for carers, and subsequently, their care recipients.

Evaluation of policies and programs is essential to monitor and reflect on the effectiveness of government policies and programs and for the implementation of evidence based practice. The National Carer Network supports the inclusion of a commitment to undertake policy and program evaluations in the Strategy. The National Carer Network believes that this should comprise of a commitment to undertake regular evaluations that are co-designed with people with disability and carers to ensure that it is appropriate and accurately captures the effectiveness of the policies and programs in meeting the needs of people with disability and carers.

The engagement of people with disability and their carers is essential in the development and design of government policy and programs to encourage and support self-determination and meet the needs of people with disability and their carers. Carers may require a different engagement approach to those used to engage people with disability due to differing availability and support needs. The National Carer Network recommends that a carer engagement plan also be included in the Strategy as it is likely to be most effective in ensuring that carer engagement is appropriate and effective. However, any engagement plan developed as part of the Strategy must include engaging carers in alignment with the

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[35] DSS (2020).

[36] Commonwealth of Australia. House of Representatives (2020) *Questions without notice, COVID-19: Disability* (Official Hansard), available online at: https://parlinfo.aph.gov.au/parlInfo/genpdf/chamber/hansardr/b8197f17-5287-4edd-8f7f-5577701ad7c3/0157/hansard_frag.pdf;fileType=application%2Fpdf

Carer Recognition Act 2010 to ensure that carers can also actively participate in shaping the disability policies, programs and services that also impact them.

Further considerations

Inclusive emergency preparedness and response

Many people with disability rely on regular support from family members and friends whose support would be crucial in preparing and responding adequately to a natural disaster or pandemic. In some cases, a carer takes primary responsibility for coordinating and implementing these plans to ensure the safety of their family member or friend, and prevent loss of life, health or property. This responsibility can also place carers at additional risk during emergencies.

The 2019-20 bushfires and ongoing COVID-19 pandemic have highlighted the inadequate level of preparedness the broader community and mainstream services have had in supporting people with disability and carers to prepare for and respond to such crises. The National Carer Network has heard from many carers who have found information and support limited in meeting their own needs and the needs of the person they care for. Appropriate accommodation, access to assistive technology or life-saving equipment, personal protective equipment (PPE) and essential food or medication have been identified by carers as being particularly difficult to obtain, often resulting in significant distress for both carers and the people they care for. [37] Carers Australia and Carers ACT highlighted the invisibility of carers during COVID-19 at the Senate Select Committee on COVID-19's inquiry into the Australian Government's response to the COVID-19 pandemic.[38]

Furthermore, for people with disability and their carers, the impact of recent consecutive crises is likely to be prolonged. As social distancing measures are rolled down, many Australians will begin to recover from recent crises, however the ongoing heightened risk of COVID-19 for people with disability and many carers who themselves are at increased risk is likely to delay the recovery of people with disabilities and their carers as they continue to self-isolate, self-fund PPE or change or reduce their education or employment to minimise risks. Targeted support will be needed for these groups to ensure no further impact of recent crises is felt and that they are able to effectively recover.

The National Carer Network believes that the Strategy should create clear responsibility and accountability for the increased inclusion of people with disability and their carers in planning and preparing for emergencies. In addition to this, the Strategy should place an onus on governments to ensure that people with disability and their carers are considered and included and receive targeted support where appropriate in COVID-19 recovery measures.

Ongoing disability reform

With ongoing reform of disability policies and programs following the Tune Review and the ongoing Disability Royal Commission, the Strategy must be comprehensive while creating space for the Strategy to develop over time based on the recommendations that arise from formal inquiries, reviews and commissions. The National Carer Network believes that the Strategy should align with emerging findings and recommendations from current reviews and create greater accountability for governments

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[37] Carers NSW (2020), *The COVID-19 Pandemic: Challenges and opportunities for carers in NSW*, available online at: http://www.carersnsw.org.au/policy/changing-systems

[38] Commonwealth of Australia. Senate Select Committee on COVID-19 (2020), *Australian Government's response to the COVID-19 pandemic, 1 July 2020*, (Official Hansard), available online at: https://parlinfo.aph.gov.au/parlInfo/download/committees/commsen/3b0504ac-bd44-4fc3-8030-90ac84c1b8ea/toc_pdf/Senate%20Select%20Committee%20on%20COVID-19_2020_07_01_7838_Official.pdf;fileType=application%2Fpdf#search=%22committees/commsen/3b0504ac-bd44-4fc3-8030-90ac84c1b8ea/0000%22

to act on these recommendations to ensure that inquiries, reviews and commissions are effective and result in improved outcomes for people with disability and their carers.

Regional and rural areas

It should be noted that people with disability and their carers living in regional, rural and remote areas are particularly disadvantaged in relation to service deficits and system interface issues, and should therefore be a priority group identified throughout the Strategy.

Conclusion

The development of a new National Disability Strategy provides great opportunity to ensure a clear, whole of government plan for increased inclusion and participation of people with disability and their carers that aligns with existing strategies and legislation. The National Carer Network believes that a key to the success of the Strategy will be the inclusion of carers, as the key supporters of people with disability, throughout all areas of the Strategy. A dual focus throughout the Strategy on the overlapping and unique needs of people with disability and their carers is likely to ensure optimal inclusion and participation of both groups.