Carers Australia VIC

Carers Victoria submission

National Disability Agreement Review
Productivity Commission Issues Paper

September 2018

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership-based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This policy paper was prepared by Carers Victoria’s Policy Team.

For information contact:
Scott Walker
Chief Executive Officer
Carers Victoria
Telephone: 03 9396 9509
Facsimile: 03 9396 9555

Website: www.carersvictoria.org.au

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Summary of Carers Victoria recommendations

Carers Victoria recommends:

- evaluation subsequent to implementation of the ICSS in providing better support for families and carers should be reported against the outputs of the NDA.
- development of a positive policy framework that sheds the low expectations of past policy settings is required to assist people with disability, their families and carers to not only aspire to, but to achieve an ordinary life.
- achievable outcomes should be subject to realistic timelines; trials and evaluations similar to those which marked the beginning of the NDIS
- Agreement have regard to the way States and Territories are delivering services to people with a disability outside the NDIS.
- assessment criteria should include identifying any policies and actions by Commonwealth, State and Territory government contradictory to the stated objective of the NDA.
- the NDA emphasises achievable outcomes for people with disability, their families and carers.
- reference in the current NDA to the importance of data collection should be retained and enhanced in a future NDA to provide confidence it the accountability and performance measures outlined.
- achievable outcomes should be subject to realistic timelines; trials and evaluations similar to those which marked the beginning of the NDIS.
- the NDA outcome of participation and social inclusion should explicitly refer to both people with disability and carers in line with the performance indicators.
- the Agreement have regard to the way States and Territories are delivering services to people with a disability outside the NDIS.

Introduction

Carers Victoria has considered the relevance of NDA within contemporary policy settings and considers there is still much to be achieved in improving participation, social inclusion, choice, wellbeing and independence for people with disability. Carers Victoria especially wants to see improved support for families and carers of people with disability and view the NDA as an essential accountability mechanism for government action. As a member of Carers Australia, Carers Victoria supports the national position contained in their submission. Our response to the issues paper is therefore focused on improving the accountability of the NDA in achieving outcomes for Victorians with disability, their families and carers.

Carers Victoria response to selected questions

Does the Commission's representation of the policy architecture supporting the NDA in figure 1 adequately capture all relevant policy areas? Is anything missing?

Carers Victoria recommends the current policy architecture supporting the NDA can be enhanced with the inclusion of the:

1. National Carer Strategy and Action Plan (2011-2014),
2. Current Specialist Disability Accommodation (SDA) Pricing and Payments Framework including any revisions made in 2018, and
3. National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2016.

The NDA should also make reference to state and territory disability and carer legislation and policies.

What framework and assessment criteria should be used to review the NDA? Is there anything missing from the proposed framework and criteria (in figure 2)? What other frameworks could be used?

Carers Victoria supports the Productivity Commission's view that the "intention of the framework is to clearly link government policy actions with the overall objective of disability policy, using performance reporting to enhance government accountability."

Carers Victoria considers what is missing from the framework is the level of support required by different cohorts of people with disability to facilitate participation, social inclusion, choice, wellbeing and independence. People with different types of disability such as intellectual disability and some people from different population groups, such as culturally and linguistically diverse backgrounds are likely to need additional support.

Families and carers play key roles in achieving these outcomes for people and should be recognised for this as well as some families and carers who require additional support in their caring role.

Carers Victoria recommends more effective alignment of all levels of government policy with the NDA. Carers Victoria is aware separate agreements between the Parties may ultimately hinder the overall objective of the NDA. For instance, the Heads of Agreement between the Commonwealth and the Victorian Governments on the National Disability Insurance Scheme can be considered undermining the overall objective of the NDA "that people with disability and their carers have an enhanced quality of life and participate as valued members of the community.

Current practice in Victorian DHHS shared supported accommodation vacancy management, is for the NDIA to allocate the place to a participant with SDA in their plan despite any expressed preference to live independently (alone or with family). This is legislated in the National Disability Insurance Scheme (Plan Management Rules) 2013, in particular rules 6.8–6.13.[1] The Framework encourages the expectation that eligible participants will conform to the status quo where choices of where they live, with whom and in what environment are made by others.

Carers Victoria recommends assessment criteria should include identifying any policies and actions by Commonwealth, State and Territory government that are contradictory to the stated objective of the NDA.

Assessing the National Disability Agreement

Purpose and Scope of the NDA

In light of developments in the disability policy landscape and intergovernmental funding arrangements, is an NDA still required?

Carers Victoria believes a National Disability Agreement is still critical to the national policy landscape to sustain a long-term approach to changing the lives of people with disability, their families and carers. However, Carers Victoria recommends a revised NDA should set clearer targets and timelines to achieve its purpose, particularly in relation to families and carers because the current Agreement is too broad to be effective.

Carers Victoria supports keeping the NDA because it is a policy that explicitly refers to ensuring carers of people with disability are well supported. Importantly, the Agreement does not stipulate the support for carers is predicated on the eligibility of the person with disability for the NDIS. Without a continuing NDA, it is likely the majority of Australians with disability who are ineligible for the Scheme, their families and carers will not have a national policy framework to address their needs.

In addition, the NDA is crucial because national reforms to services and supports specific to carers have lagged implementation of reform to disability policy (as well as aged care, mental health and health policy). The proposed Integrated Carer Support Service (ICSS) is not planned to fully roll out until late 2019. Carers Victoria recommends evaluation subsequent to the implementation of the ICSS in providing better support for families and carers should be reported against the outputs of the NDA.

Carers Victoria envisages a revised NDA would provide an important impetus for the Victorian Government to actively ensure better support for families and carers as well as people with disability. While the Victorian Government has shown a commendable commitment to address the social and economic exclusion of people with disability as well as high rates of violence, poor educational and health outcomes of the past with its current State Disability Plan *Absolutely Everybody*, its commitment to families and carers is ad hoc. For example, in its Annual Report (2017), there are no measures outlined including families and carers in achieving the strategies of the State Disability Plan. Moreover, references to family and friend carers are used interchangeability with disability support workers.[2]

While a Carer Recognition Act was legislated in Victoria in 2012, Government reporting is largely limited to information dissemination and promotion of the cares relationships principles within government departments. However, this appears to more successful in some branches and divisions than others.

The Victorian Department of Health and Human Services (DHHS) publishes notes on its Compliance with the Carers Recognition Act 2012. According to its Annual Report (2016-2017), “the Department has taken all practical measures to comply with its obligations under the Act”.

Carers Victoria strongly supports the recently launched inaugural Victorian Carer Strategy 2018-2022. Carers Victoria has advocated for a whole-of-Government Carer Strategy, given the seismic reforms occurring in disability, mental health, aged care and health services. However, the commitment “to strategies that focus on improving outcomes for carers” is stated without a framework for measuring the impact of these strategies. Moreover, the Victorian Carer Strategy does not specifically reference the National Disability Agreement or include measures to determine the efficacy of the strategies in achieving outcome (c) of the NDA – [that] families and carers are well supported.

A revised NDA with a national approach remains critical given the interconnectedness between Commonwealth and State and Territory funding. Due consideration should also be given by COAG to identifying shared roles and responsibilities across the NDA and the five other National Agreements in achieving outcomes for people with disability, their families and carers.

If so, how can the NDA remain policy relevant in an evolving policy environment?

The NDA can remain policy relevant by being regularly reviewed to ensure it reflects current roles and responsibilities, funding arrangements and programs.

The NDA can remain relevant for families and carers by ensuring there continues to focus on outcomes that meet their dual needs as consumers who utilise disability services in concert with or on behalf of a person with disability and as individuals in their own right with improved opportunities to achieve physical and mental wellbeing, economic security and social participation.

> *Support is only provided with the disabled person in mind. I am dismayed that now I am also disabled thanks to caring for two family members, I am still INVISIBLE to CARER PROVIDERS. NO ONE IS LISTENING TO ME. NO ONE SEES ME. NO ONE GIVES A DAM (sic) ABOUT ME.*
>
> Respondent to 2017 Carer Survey

What should be the purpose of the NDA? Is it an effective accountability mechanism for government actions relating to disability? If not, what are the more effective mechanisms that could be used?

The purpose of the NDA should be to ensure State and Territory governments work in concert with the Federal government to *regularly review and determine* each parties' roles and responsibilities in delivering its objectives. Unfortunately, its effectiveness as an accountability mechanism has been limited so far. However, Carers Victoria believes the NDA can be an effective accountability mechanism if the right measures are included and reporting is public.

What should be the scope of the NDA? Should it continue to cover all people with disability? What services should it cover (such as specialist disability services and/or mainstream services, including mental health, healthcare, aged care, education, transport, housing and justice)?

The NDA should cover all people with disability of all ages, their families and carers, including people eligible for individualised support packages under the NDIS. This will ensure a cohesive approach to disability across Australia. Separating specialist disability services from mainstream services, including mental health, healthcare, aged care, education, transport, housing and justice will invariably lead to a siloed approach for people with disability their families and carers.

The current NDA makes reference to the importance of data collection and the National Disability Research and Development Agenda. Carers Victoria recommends these should be retained and enhanced in a future NDA to provide confidence it the accountability and performance measures outlined.

Is there a coherent link between the NDA and other related agreements, strategies and policies, such as the NDS, the NDIS and State and Territory disability strategies?

Carers Victoria is very mindful the NDIS remains just one aspect of broader policy frameworks and service delivery for people with disability, their families and carers. As discussed above, the NDIS is rapidly and significantly altering the social services landscape – it does not just affect people with disability eligible for individualised support packages but potentially everyone in the community. When the dust settles, the service delivery landscape will be fundamentally different. However, the NDIS is only expected to provide individualised funding packages to 460,000 Australians, well short of the 4.3 million Australians with disability and 2.7 million carers.[3]

While the NDA signals intentions for Governments to better support families and carers, a key mechanism for doing so (albeit for a small number of carers) is the NDIS Act 2013. Yet carers receive only nominal recognition in the Act (the Act). Section 3 (3)(c)(ii) of the Act states regard is to be had to the *Carer Recognition Act 2010* (the *Carer Recognition Act*). The *Carer Recognition Act* includes a Statement for Australia's Carers (section 6) which recognises and respects the critical role carers have in the lives of people with care and support needs. It emphasises partnerships in decision-making with service providers, taking into account carers' own needs within and beyond the caring role, and providing them with timely support.[4]

However, the legislation, where 'regard' of the Carer Recognition Act does not confer any legal duties on the NDIA.

The *NDIS Act 2013*, further nominally recognises care relationships at:

- section 4(3) – 'people with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime'.
- section 4(12) - 'the role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected'.
- section 5(e) - 'the supportive relationships, friendships and connections with others of people with disability should be recognised'.
- section 31(c) - 'the preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should, so far as reasonably practicable…consider and respect the role of family, carers and other persons who are significant in the life of the participant'.

Again however, this nominal recognition places no legal duty on the NDIA to assess carer needs or provide reasonable and necessary supports to sustain the care relationship or consider the willingness of the carer to continue to provide the same level of informal supports.

There is a requirement under the Act to consider informal supports provided by carers, recognising the cost efficiencies of informal supports. Specifically, in allocating funding to participants, the planner must consider what is reasonable to expect families, carers, informal networks and communities to provide [S34(1)(e) NDIS Act]. The NDIS Rules for participants reiterates this at Rule 2.3(e) ‘the funding or provision of the support takes account of what is reasonable to expect families, carers and informal networks and the community to provide’. In deciding what is reasonable for families to provide, the NDIA is to ‘consider’ [Rule 3.4(b) Supports for Participants Rules]:

- the extent of any risks to the wellbeing of the participant arising from the participant’s reliance on the support of family members, carers, informal networks and the community
- the suitability of family members, carers, informal networks and the community to provide the supports that the participant requires
- the extent to which informal supports contribute to or reduce a participant’s level of independence and other outcomes, and
- the desirability of supporting and developing the potential contributions of informal supports and networks within their communities.

The following factors may be considered with regards to the suitability of carers:

- the age and capacity of the participant’s family members and carers, including the extent to which family and community supports are available to sustain them in their caring role
- the intensity and type of support that is required and whether it is age and gender appropriate for a particular family member or carer to be providing that care, and
- the extent of any risks to the long-term wellbeing of any of the family members or carers (for example, a child should not be expected to provide care for their parents, siblings or other relatives or be required to limit their educational opportunities).

Other instances where the NDIA must consider the care relationship are framed negatively. For example, the funding of Specialist Disability Accommodation whereby the parent or parents of the participant cannot reside in the dwelling [Rule 6.1(c) SDA Rules 2016], or the dwelling cannot be the family home [addendum to the Terms of Business, p 8]. Further, where relatives are registered SDA providers they ‘must not preference one participant over another, in that residents of SDA must be afforded the same treatment, rights and choices as all other residents’ [addendum to the Terms of Business, p 12]. The purpose here is not to comment on the individual merits of each of these ‘safeguards’, but to highlight most obligations the NDIA has to care relationships are negatively constructed. In contrast the NDA provides an opportunity for a more positive approach to supporting people in care relationships.

An example of a more positive approach is in the United Kingdom with the introduction of personalised supports and individual budgets has been more incremental, building on existing service delivery rather than a complete replacement of current State or territory provided supports. The *UK Care Act 2014* entitles carers to an individual needs assessment, in addition to the person with disability. Further, 'the Care Act 2014 has given parity to carers, who are now entitled to have their own eligible needs met through a carer's personal budget'.

Notwithstanding the relatively small scope but large impact of the NDIS, better links between State and territory disability strategies, the National Disability Strategy and the NDA will help to address service delivery gaps both for NDIS participants and people who are not eligible for the NDIS, as well as their families and carers.

Objectives, outcomes and outputs of the NDA

Are the objectives, outcomes and outputs of the NDA relevant in the context of contemporary policy settings? Are they clear and consistent?

The objectives, outcomes and outputs of the NDA are still relevant in the context of contemporary policy settings. People with disability, their families and carers should be supported by the community to achieve economic participation and social inclusion; to enjoy choice, wellbeing and the opportunity to live as independently as possible and families and carers should be recognised for their contribution and supported in their caring role. In relation to carers, the Agreement should stipulate carers are well supported to identify and address their own needs, even if this means reducing their caring role in order to pursue the carers goals and aspirations.

However, the current Agreement does not make clear enhancing the quality of life for people with disability, their families and carers requires redressing decades of policies embedding low expectations for people with disability, their families and carers, poor service design and heavily rationed service delivery.

> *[My caring role involves trying] to assist in accessing education and social activities where the bar is appropriately set rather then (sic) settling for the low expectations often put on her.*
>
> Respondent to 2017 Carer Survey

Further to this, the implementation of the NDIS has demonstrated even the NDIA, has its own challenges in supporting people with disability to live as independently as possible. The nominal recognition of carers in the Act has been discussed above, however, Carers Victoria is also concerned about participants' own needs. Recently at a hearing of the Administrative Appeals Tribunal, the NDIA argued for a participant to reduce face-to-face socialising, working and contributing to his community in a voluntary capacity and to instead do so from his home via digital technologies such as Skype or telephone to reduce the cost of taxi use.[5]

Funding for Specialist Disability Accommodation (SDA) is another area where legacy policies of States and Territories have contributed to a high level of inertia by the NDIA to fund participants outside the 'group-home' scenario or other institutional settings. In the Barwon region of Victoria, 124 people aged under 65 were admitted to residential aged care despite the NDIS being fully rolled out in the region [6]

Underpinning participation at the most basic level for people with disability and carers are income support payments. The policy landscape for these payments is also very different from 2013. Currently about 60 per cent of all new applicants for DSP are rejected on their first application.[7] Carers seeking income support are now unable to claim back payment from the day of notification. Carers Victoria consistently receives feedback from carers of people with mental illness, their applications for Carer Payment are often rejected because their role is not assessed in the same way as carers of people with physical or intellectual disabilities.

How do they, or should they, relate to the six outcomes articulated in the NDS and the outcomes of the NDIS?

The objectives, outcomes and outputs of the current NDA are somewhat related to the six outcomes articulated in the National Disability Strategy. Carers are often utilised as a resource in the disability services, health and aged care systems where their needs are rarely identified and met in their own right. The National Disability Strategy replicates this by avoiding mention of specific actions that would improve the lives of families and carers in their own right. This is illustrated by the fact the only explicit reference is made in Priority 4 "making sure community support networks are available to provide information and support to families and carers".

The National Disability Insurance Scheme is a key action under the Strategy and it currently appears all the eggs of the current NDS have been placed into the basket of the NDIS as the most major reform in social policy since the establishment of Medicare. However, it is necessary to reiterate the number of people eligible for NDIS individualised support packages compared with Australians with disability who are not eligible is low: only 10 per cent of the one million Victorians with disability will be eligible to receive individualised support packages over their lifetime. Moreover, the community has seen many challenges with the implementation of the NDIS. Families and carers are significantly involved in pre-planning, planning and plan implementation but positive outcomes are not necessarily enjoyed by themselves.

> *[My role has involved] co-ordinating the entire thing, including hundreds of hours of meetings and preparing documents. I then had to put dozens of hours into setting the package up when we finally received it, including negotiating a dispute between services who got in a wrangle about the support they were providing to my brother.*
>
> *Respondent to 2017 Carer Survey*

The objectives, outcomes and outputs of the NDA should be seen as the foundation of national policy for people with disability, their families and carers. Carers Victoria is optimistic changes to the NDA have the potential to impact the entire architecture of disability and carer policy.

To what extent should the outcomes be aspirational (worked towards but not necessarily achieved within a specified time period), versus achievable within a defined period?

Carers Victoria does not believe aspirational and achievable outcomes need to be mutually exclusive. Some outcomes are more aspirational than others; for example, “families and carers are well supported”. However, an achievable outcome may be measuring the number of families and carers whose own needs are identified and met within a specific time frame.

Carers Victoria recommends the NDA emphasises achievable outcomes for people with disability, their families and carers. These cohorts have much lower participation in economic and social activities other Australians take for granted. While the situations of individual carers and families are diverse, there is a strong and growing body of evidence in the literature that health, social and economic problems disproportionately affect the caring population in comparison to the general population.

Potential outcomes to reduce the exclusionary impacts of disability must be sufficiently complex and include the impacts experienced by both people with a disability, their family and carers – particularly those who provide intensive and long-term care.

Carers Victoria recommends the development of a positive policy framework that sheds the low expectations of past policy settings to assist people with disability, their families and carers to not only aspire to, but to achieve an ordinary life.

Further to this, Carers Victoria recommends achievable outcomes should be subject to realistic timelines; trials and evaluations similar to those which marked the beginning of the NDIS. However, such trials and evaluations can only be useful if learnings are made public prior to decisions made about proceeding or terminating the trial. These can be developed for innovative supports and services, particularly those which will meet the needs of people who do not receive individualised funding packages through the NDIS. States and Territories must be given the opportunity to consult their own communities “consistent with local needs and priorities” in order to develop plans which align with national goals.

Further refinement of outcomes should be subject to community consultation. For instance, participation in employment requires nuanced attention to the gender, age and time spent out of the paid workforce by the carer in order to develop a strategy to increase economic participation.

Carers Victoria recommends the NDA outcome of participation and social inclusion should explicitly refer to both people with disability and carers in line with the performance indicators.

Should there be specific performance measures linked to the outputs and if so, what should they be?

Carers Victoria recommends the inclusion of specific performance measures linked to the NDA’s outputs. Notably, the NDA’s Performance Benchmarks for carers only stipulates the “Parties agree that further work will be undertaken to develop a benchmark with a quantifiable target for Outcome (c)…”, however, it does not appear this occurred. Indeed, it can be argued with the NDIS Act (2013), families and carers have been effectively marginalised.

Carers Victoria acknowledges carers and caring roles and relationships are diverse and this assumption underpins the comments made about each of the current performance indicators in relation to carers.

Carers Victoria recommends the current performance indicators relating to carers (g – i) remain but require further development.

(g) proportion of carers with disability participating in the labour force;

Carers Victoria recommends this performance indicator remain with a more nuanced focus on carers with particular attention paid to the workforce participation of carers. In Victoria, only 58 per cent of all carers participate in the workforce; of the State's population of primary carers (239,000) 42 per cent participate in the workforce. Carers Victoria recommends any emphasis on workforce participation must be done by taking into account the effects of time out of the workforce, age and gender. As Carers Australia's submission to *the Department of Jobs and Small Business Discussion Paper: The next generation of employment services* makes clear, "carers, especially primary carers, seeking employment after a significant time out of the workforce share many of the characteristics of other disadvantaged job seekers at risk of economic disadvantage."[8]

Young carers are also likely to require additional support to complete their education and to develop their career goals. A 2017 report by the Australian Institute of Family Studies (AIFS) highlighted disadvantage among young carers due to their care responsibilities. This research taken from Growing Up in Australia: The Longitudinal Study of Australian Children (LSAC) identified young carers in Year 9 performed lower in reading and numeracy skills. Of the 3,341 children in the cohort who completed the survey, 39 per cent (40 per cent of boys and 37 per cent of girls) reported providing some type of care. Caring for multiple people was also not uncommon, with almost 20 per cent of these young people disclosing care relationships with more than one person. Compared to their non-caring peers, in reading, boys were 1.9 years behind and girls were 1.6 years behind their peers when they spent two or more hours per day as a carer. It has been very difficult to find rich, large-scale data, to identify the extent of young carer educational disadvantage, however the LSAC results are likely to reflect the circumstances of a much larger age cohort of young carers.

Further, the NDA must appreciate the issue of Australia's ageing population. In Victoria there are currently 5,900 primary carers over the age of 65 looking after an adult child with disability at home. Parent of adults with disability have not yet transitioned from 'employment' to 'retirement' in ways that remotely resemble their peers or their own parents. Transition and/or succession planning is a known challenge for parents of adults with disability. Workforce participation is not relevant to carers in their 70s, 80s or 90s, however, a good retirement, without financial stress is relevant to this cohort.

(h) proportion of carers of people with disability who report their health and wellbeing as positive;

Carers Victoria recommends this performance indicator should remain.

Carers experience poorer mental health outcomes to people who do not care[1].[9] [10] A lack of support for caring roles, along with specific characteristics of care relationships can increase risk of mental ill health and stress related issues. This includes depression with 56 per cent having at least moderate depression and one fifth of them having severe depression,[11] as well as experiencing high levels of anxiety[12] psychological distress and lower perceptions of self-efficacy and personal well-being.[13][14] This can remain even after care roles have ceased .[15] Some research also suggests carers are significantly more likely to have suicidal thoughts than non-carers due to feelings of hopelessness.[16] [17]In addition, mental health carers have worse self-reported mental health outcomes than carers who are not supporting a person with mental illness.[18]

(i) Proportion of primary carers of people with disability who are satisfied with the range of services available, and with the adequacy and quality of services provided, to the person with disability and to the carer.

Carers Victoria recommends this performance indicator remain but be clearly differentiated between satisfaction with services for the person with disability and satisfaction with services for the carer in their own right. Carers often report the availability and quality of disability services has a direct impact on their ability to pursue their social aspirations, economic participation and ability to study. However, as illustrated by the following quote, carers may

> *My employer is very understanding. I have missed many hours of work taking my husband to medical appointments or staying home when carers are unavailable. I am also basically always tired so never quite as effective as I should be when at work.*
>
> Respondent to 2017 Carer Survey

also require a range of other supports such as flexible workplaces and career development support.

Measures of satisfaction should be developed and conducted by an independent agency, such as the Australian Institute of Health and Welfare, however, the parties to the Agreement should also be informed by the community and peak bodies representing carers.

Carers Victoria also suggests more context is needed for this performance indicator. Currently, the Victorian Carer Recognition Act (2012) does legislate service providers to include carers' views when they plan and delivery services that affect the care relationship. However, a survey conducted by Carers Victoria in 2017 which collected over 1000 responses shows only 30 per cent of respondents believe “care support organisations ***always*** include carers' views when they plan and delivery services that affect the care relationship”. The Victorian Carer Recognition Act does not include any measures to enforce the inclusion of carers’ views or needs in any service design or delivery. This resonates with comments made earlier regarding the NDIS Act 2013 which only provides nominal recognition of carers and no legal duty to consider their needs.

How have the roles and responsibilities of Governments changed since the NDA was updated in 2012? Are roles and responsibilities clear?

It is clear the roles and responsibilities of Governments have changed since the NDA was updated in 2012. Legislation and funding of disability services for people with disability eligible for individualised funding packages through the NDIS will rest solely with the Commonwealth government after full roll-out in 2019. The regulation, service quality and assurance of services provided for NDIS participants are moving to the Commonwealth with the establishment of the NDIS Quality and Safeguards Commission.

The role of the Victorian Government in disability services has changed dramatically since 2012 from a direct funder and service provider to maintaining a legislative and regulatory function. In light of its changed function, the State Government has recently introduced legislation to establish the Disability Worker Registration Board of Victoria and the Victorian Disability Worker Commission in addition to introducing the first disability abuse prevention strategy. Moreover, the Department of Health and Human Services is currently divesting itself of service delivery in its supported accommodation properties and out-of-home respite facilities. Five Supported Independent Living (SIL) providers have just been announced after the Government called for expressions of interest from providers who could demonstrate their capacity to deliver services across the state.

The Victorian Government maintains oversight of the transitioning disability landscape by convening the Victorian NDIS Implementation Taskforce and sub-working groups including participant readiness, participants with complex needs sub-working group and housing working group. Carers Victoria participates in these important consultative mechanisms which involve people with disability, the NDIA, service providers, academics and other public servants. Carers Victoria commends such opportunities to share information with key stakeholders and the Victorian Government's commitment to ensure resources are available to address transition-specific challenges. For instance, the State Government has established two teams to effectively address challenges raised in the NDIS transition: an Intensive Support Team and Supported Access Team. The Intensive Support Team is intended to support NDIS participants with complex needs who also interact/engage with Victorian agencies such as Justice, Child Protection and Health. The Supported Access Team undertakes active outreach to individuals and communities who may not wish to engage with formal services such as those which can be delivered by the NDIS. This team also ensures individuals who were included in 'defined programs' by DHHS (and were automatically eligible for the NDIS) but who the NDIA could not effectively contacted.

In relation to carers, the Victorian Government's responsibilities have been less clear. Carer recognition has been legislated since 2012 and the inaugural Victorian Carer Strategy launched in July 2018. By launching its whole-of-government Victorian Carer Strategy 2018-22 which recognises carers' rights as citizens, the Victorian Government has begun to strategically address the unique and specific needs of people in care relationships across areas such as employment, health, education and financial disadvantage. The strategy reflects the breadth of carer experiences, including the unique needs of both young and older carers.

Carers Victoria commends the Victorian Government's intention to "monitor and review data from various services to see what progress is being made as" changes are introduced. Similarly, the intention to include carers when conducting annual forums to review the strategy implementation from July 2019 is a positive step in supporting a community of empowered carers.

However, we also expect the Victorian Government to:

- Provide clear timelines for developing new program and service guidelines
- Develop frameworks to connect data from a range of government departments
- Develop a comprehensive community engagement plan
- Ensure carers who are engaged in decision making and monitoring of the Carer Strategy reflect the diversity of Victoria’s carers as well as address the barriers carers can face in engaging with feedback mechanisms
- Establish an independent review of the current Strategy commencing in 2021
- Determine the new priorities for the next Strategy in 2021

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How has the introduction of the NDIS impacted on access to services for people not eligible for the NDIS?

As people not eligible for the NDIS in many cases (despite the fact 31% of Victorian carers report living with a disability themselves),[19] carers have been significantly impacted by its introduction. Funding for the NDIS has progressively transitioned from the following Commonwealth programs as regions in Victoria have or will transition to the Scheme: Respite support for carers of young people with severe or profound disability, Young Carers Respite and Information Services, Mental Health Respite: Carer Support and Better Start

It is unclear what work the Governments are doing to map the emerging service gaps produced by changes in funding to the non-government sector. For example, carers have consistently reported to Carers Victoria their carer support groups are no longer being funded because service providers are no longer block-funded, and carers are no longer a target group of either the Commonwealth Home Support Program, disability or mental health services.

Moreover, the transformation of the social service landscape in the wake of the NDIS and other reforms in aged care cannot be underestimated. Some organisations which relied on block funding have not been able to successfully transition to the business model underwritten by the NDIS. This may be due to the organisation’s own inability to innovate and respond to a changing market, however, there have been several independent reports stating the funding models embedded in the NDIS are not viable to sustain organisations, quality staff retention and service delivery.[20] [21]It is likely without a comprehensive community services sector, families and carers will be required to provide more intensive levels of caring than before.

Should the agreement have regard to the way States and Territories are delivering services to people with a disability outside the NDIS (for example, through mainstream services or through specialist disability services)? If so, why?

State and Territory Governments no longer fund and regulate basic community care for people under the age of 65 in line with their principal responsibility for delivery of other disability services under the Agreement. An exception is the Victorian government’s commitment to provide limited funding for a basic Home and Community Care Program for Younger People (HACC-PYP) for people aged under 65 with support needs who are not eligible for individualised funding under the NDIS. However, demand for this program currently exceeds supply, especially for community nursing services. This has significant impact on carers required to provide additional care in the absence of formal services. Carers Victoria is aware of carers, who are required to pay for these services privately or, are no longer able to access respite care services due to the person receiving care’s need for nursing services.

The Victorian government is still responsible for funding and delivering disability services prior to full NDIS roll out, yet little work has yet been done in mapping emergent service gaps for ‘consumer’ or ‘carer’ cohorts.

The interface between specialist disability services and mainstream services such as transport, health, education and employment are also undergoing significant transformation. Each State and Territory government is developing its own strategies and mechanisms for these interfaces. However, there continues to be a reluctance in some areas of government to support and enforce the best opportunities for people with disability, their families and carers.

> *I've worked out a special plan with my school where I'm doing four subjects over three years, instead of five subjects over two years. Doing the six subjects that's normal for my school - I just wasn't able to function and I was pretty much drowning in work and I actually had to go to my year level coordinator because I knew I wasn't coping. It's definitely released the stress load but it's still kind of stressful.*
>
> Participant in young carer consultation 2017

> *Education – children are all home educated because schools do NOT assist special needs kids find their special gifts. Nor do they provide support and time for the special needs child to focus on what could be the only real way they can earn money or have self esteem as adults – be it science or writing or the arts. Schools also do NOT protect special kids in any effective way for bullying. We experienced first hand all of these issues and it's clear our former public school was typical for the above issues.*
>
> Respondent to 2017 Carer Survey

Carers Victoria strongly recommends the Agreement have regard to the way States and Territories are delivering services to people with a disability outside the NDIS.

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