

# Co-Design Summary Report:

SUMMARY OF THE CO-DESIGN PROCESS TO DEVELOP THE  
NSW CARERS STRATEGY & ACTION PLAN 2020-2022

August 2020

# Contents

## Introduction ..... 3

Background

Departmental observations

## Summary of key findings..... 5

**Priority 1** Carers have better access to information, services and supports

**Priority 2:** Carers will be recognised, respected and empowered

**Priority 3:** Carers have improved financial wellbeing and economic opportunities

**Priority 4:** Carers have better health and wellbeing

## Co-design methodology ..... 21

Carer co-design workshops

Online survey for carers

Future co-design work

## References ..... 27

### Copyright

This publication is protected by copyright. With the exception of (a) any state arms, logo, trade mark or other branding; (b) any third party intellectual property; and (c) personal information such as photographs of people, this publication is licensed under the Creative Commons Attribution 4.0 International Licence. The licence terms are available at the Creative Commons website at: <https://creativecommons.org/licenses/by/4.0/legalcode>

The Department of Communities and Justice requires that it be attributed as creator of the licensed material in the following manner: © State of New South Wales (Department of Communities and Justice) 2020

You may also use material in accordance with rights you may have under the Copyright Act 1968 (Cth), for example under the fair dealing provisions or statutory licences.

The use of any material from this publication in a way not permitted by the above licence or otherwise allowed under the Copyright Act 1968 (Cth) may be an infringement of copyright. Infringing copyright may expose you to legal action by, and liability to, the copyright owner. Where you wish to use the material in a way that is not permitted, you must lodge a request for further authorisation with the Department of Communities and Justice.

### Disclaimer

The Department of Communities and Justice does not guarantee or warrant, and accepts no legal liability whatsoever arising from or connected to, the accuracy, reliability, currency or completeness of any material contained in this publication.

Information in this publication is provided as general information only and is not intended as a substitute for advice from a qualified professional. The Department of Communities and Justice recommends that users exercise care and use their own skill and judgment in using information from this publication and that users carefully evaluate the accuracy, currency, completeness and relevance of such information. Users should take steps to independently verify the information in this publication and, where appropriate, seek professional advice.

### Enquiries

Enquiries relating to this publication or use of material in this publication should be directed to: Department of Communities and Justice, 4 Cavill Ave, Ashfield or email [CARERSTR@fac.nsw.gov.au](mailto:CARERSTR@fac.nsw.gov.au)

# Introduction

This report summarises the approach and key findings from the co-design process used to develop the NSW Carers Strategy 2020–2030.

# Background

The NSW Carers Strategy 2020-2030 is the NSW Government's ten-year plan to better recognise and support people who take on a caring role. It is a whole of government and whole of community approach to supporting the more than 850,000 carers in NSW.

We will develop action plans every two years to support the ten-year strategy. These action plans will capture the initiatives that agencies across government and the non-government sector will deliver to support carers.

This work will support the Department of Communities and Justice (DCJ) and partner agencies to meet their obligations under the [NSW Carers \(Recognition\) Act 2010](#). This Act requires public sector agencies to recognise and value carers, and consult carers on policy matters that impact them.

DCJ co-designed the strategy with a wide range of carers and other stakeholders through a multi stage process including conducting workshops and an online survey to identify carer priorities and then engaging with individual stakeholder agencies to draft possible solutions in response to the identified priorities.

This approach aligns with the Department's approach to include the client voice to ensure that we continue to invest in evidenced-based initiatives that help clients reach their aspirations. It also ensures the strategy is relevant and practical for carers, providers, NSW government agencies and the broader community.

We also conducted a review of recent research and evaluations to inform this strategy. This included the 2016 review of the [Carers \(Recognition\) Act 2010](#) and the review of the first NSW Carers Strategy 2014-19. We considered gaps in the current service system and identified where we could have the greatest impact for carers in NSW.

The strategy reflects the changing service landscape for carers. In particular, the new national Carer Gateway services which commenced in April 2020.

# Departmental observations

**The Department of Communities and Justice (DCJ, formerly FACS) noted that many of the issues many of the issues raised in Stage 1 are not new. They represent ongoing issues for carers and were raised in our previous strategy. These include:**

- lack of information and need for more services
- lack of recognition and respect for carers by the community
- need for flexibility at work so carers can balance caring and work
- people not self-identifying as carers and missing out on services and supports as a result
- stigma and shame due to lack of understanding and respect by services providers and the community
- difficulty accessing services
- feeling excluded by services.

**Other key issues raised in our co-design process appear to be existing issues that have intensified for carers compared to our previous consultation process five years ago. These include:**

- financial stress
- the complexity of navigating complex service systems and managing support packages
- very high levels of burn out and stress.

**Some of the key issues raised by carers are new challenges that have emerged from the significant reforms underway in the disability and aged care systems. These include:**

- carers are overwhelmed by the complexity of the service system
- lack of skills and difficulty navigating information and services online and therefore missing out on information and support
- carers have to fight to access disability services through the NDIS
- difficulty navigating the service system and managing supports
- carers struggling to get respite and supports for themselves
- carers struggling to get any face-to-face assistance to navigate supports
- carers need to increasingly coordinate all aspects of care
- difficulty accessing aged care support presents new challenges (including waitlists)
- changes in service providers.

We used these findings to inform stage two of the co-design process. Stage two focused on developing and testing actions for inclusion in the first Action Plan 2020-2022.

# Summary of key findings

This report synthesises and summarises the key findings from the two stages of the co-design process.

We have organised the findings into the four key priorities that emerged through the co-design process in stage 1. These priorities underpin the strategy and action plan developed in stage 2.



## PRIORITY 1

Carers have better access to information and supports



## PRIORITY 2

Carers will be recognised, respected and empowered



## PRIORITY 3

Carers have improved financial wellbeing and economic opportunities



## PRIORITY 4

Carers have better health and wellbeing

PRIORITY 1



## Carers have better access to information, services and supports

“

**Knowing where to go is so important as this helps you empower yourself as a carer.**

Carer at co-design workshop — 2019

“

**Because my husband is still of working age, we fall through the cracks for many of the services as he doesn't qualify for aged care. Our peer support is almost zero as all of our friends and most family still work. Finances are a fine tuned balancing act as I can only work a number of hours per week on the carers payment and need to be available to take my husband to numerous medical appointments.**

Carer at co-design workshop — 2019



## What carers told us

- Carers told us they can only care well if they have services and supports for themselves as well as the people they care for. However, in all workshops and the online survey, carers told us they are overwhelmed by the complexity of the service system. Carers struggle to know what help and support is available, where to find it and how to access it. They need help to find and navigate services, particularly the NDIS, My Aged Care, Carer Gateway, myGov and Centrelink.
- Many carers told us they have to fight to get access to services. They spend considerable time applying for services and managing supports, particularly NDIS plans. This includes gathering evidence for assessment, re-telling their story and justifying the need for services.
- Many carers' responsibilities have intensified due to NDIS-related service changes and changes to My Aged Care. Many carers feel there has been a reduction in carer services and this has intensified their needs.
- Carers struggle to know what help is available and where to find it. Information is hard to find, not integrated or linked, and located in multiple places. In our online carer survey, more carers living in outer Sydney, regional rural/remote areas (39%) said that knowing what help is available was not working, compared to other carers (30%).
- Digitisation of information and access to government services creates additional barriers for carers, many of whom do not have access to the internet or the skills to navigate services online. Access issues included cost of data and devices, and lack of internet coverage.
- Transport is a major issue for carers. There are limited options, high associated costs and barriers to accessing transport to access services for the person they care for and themselves, particularly in non-metropolitan areas.



Aboriginal carer co-design workshop Blacktown 2019

## What carers told us would help them

Overwhelmingly, carers told us they want regular, ongoing, face-to-face peer support with other carers who understand them, know how to navigate the system, and can share experience and information. In our online survey 20% of carers said that peer support was the key thing that led to a positive outcome when they needed support.

- Carers want to see an investment in carer-specific services. In particular, carers want accessible, affordable, quality carer respite, so they can take a break from their caring role.
- Carers want face-to-face and localised assistance to help them navigate the system, work out what they need and how to access supports.
- Carers want it to be easier to access information online. They want all relevant information brought together in one place, with hyperlinks to additional information and support.
- Many people who have caring responsibilities do not self-identify as 'carers'. As such, information needs to be accessible at service touchpoints throughout the carer journey. Information needs to be available in places carers visit, not necessarily carer-specific sites.
- Information needs to be reliable, easy to understand and appropriate for all carer groups. For example, carers of people with dementia want appropriate, condition-specific information at key points along their carer journey. All carers identified GPs as a critical point for them to receive information.
- Aboriginal and Culturally and Linguistically Diverse (CALD) carers want information delivered face-to-face. They want to receive the information from someone local, who they trust, and who understands both the system and their culture.
- Carers want more education and training opportunities to build their knowledge, skills and confidence in their caring role.
- Aboriginal carers want mobile or pop-up information hubs with local services and people available for them to talk to and ask questions.
- CALD carers want culturally appropriate services in language for the people they care for (so they can use them and not be so reliant on their carer).
- LGBTQI carers want to receive information and support from 'rainbow-friendly' services.
- Some carers, particularly older carers, need support to learn to use online services.
- Carers need more reliable, affordable and accessible transport options. This is particularly true for carers living in rural and regional NSW. Suggestions include subsidies to reduce car registration, reduced parking fees for carers and Uber passes rather than taxi vouchers.
- Service providers and health professionals need additional training so they understand the diversity of carer needs and refer carers to appropriate services.



## What we know

- Increasingly, government services rely on individuals having access to computers, smart phones and the internet, and the knowledge of how to use them. Older adults, people living in rural or remote areas, Aboriginal people, and people from CALD backgrounds are the most digitally excluded groups in Australia. As such, carers from these groups may not be able to access the services and support they need.
- Some Aboriginal carers have difficulty accessing services due to a combination of a number of factors including: unable to access information, lack capacity to navigate the 'system' and difficulty processing paperwork in the required time, resulting in social exclusion from receiving payments or services.<sup>1</sup>
- Many carers suggest there has been a reduction in the level of support for people with mental illness and their carers. This is likely to increase pressure on carers and impact on other parts of the service system.<sup>2</sup>
- There is high unmet demand for aged care services. This means many carers can't access adequate supports and have increased care responsibilities. The Australian Institute of Health and Welfare (AIHW) reports that at 31 December 2018, 123,000 people nationally were waiting for Home Care Packages at their assessed level. 54,000 people had been offered lower level packages. Consumers had an estimated wait time of more than 12 months for all except Level 1 packages.<sup>3</sup>
- Carers consistently identify peer support as a priority. 79% of respondents to the 2014 Carers NSW survey rated peer support as useful<sup>4</sup>. In addition, over 30% of respondents to the 2018 Carers NSW Survey said they would like to access more peer support<sup>5</sup>. Multiple studies have shown peer support helps to improve outcomes for carers, for example by reducing burden and depression for carers of people with dementia<sup>6</sup> and contributing to carer wellbeing. Factors contributing to an effective peer support program include peer leadership, family involvement and professional facilitation or co-facilitation<sup>7</sup>. Studies suggest they are particularly beneficial for carers of people with mental illness in providing valued emotional and practical support<sup>8</sup>.
- The 2017 Productivity Commission found many concerns were raised over the lack of respite supports in NDIS plans.
- Lack of adequately funded respite in NDIS plans also appears to be creating a disincentive for providers to supply these services. It is noted that in late 2019, the NDIA included respite in the pricing guide.



**Peer support is the most valuable of all resources. The information shared and gained from lived experience is invaluable.**

**Carer peer support programs can improve carer access to information. Being with friends that are also carers allows a broader exchange and informing from carer to carer.**

Carers at co-design workshop  
— 2019

PRIORITY 2



## Carers are recognised, respected and empowered

“

**I don't feel that any of them have much awareness. My caring role is invisible to most.**

**I find it incredibly difficult to ask for help. I feel I should be able to cope on my own.**

Carer at co-design workshop — 2019

“

**My younger brother has a disability but we never thought about it, I used to carry him on my back. I didn't see any difference.**

Aboriginal carer at Aboriginal co-design workshop — Dubbo 2019

“

**Carers need to be supported to remain proud and deadly, to survive and thrive while taking on their caring role.**

Aboriginal Carer at co-design workshop — Blacktown 2019

## What carers told us

- In most workshops, carers told us that they do not identify as or connect with the concept of being a 'carer'. People with caring responsibilities see themselves as someone looking after a family member or loved one.
- There are negative associations with being a carer, including feelings of stigma and shame. This can prevent carers from seeking help.
- Aboriginal families may fear being judged harshly or risking child protection intervention if they seek help from government agencies. This may prevent families from accessing support services.
- Carers of people with dementia, mental illness and young carers also told us they experience stigma. They are embarrassed to ask for help and feel they have to manage public judgement.
- Carers experience stigma at work and feel unable to disclose their caring role because they fear that their employer will not be understanding or supportive.
- Carers feel their skills, experience and knowledge are not valued. In our online survey, carers felt least recognised, respected or valued by their workplace (21%) and the media (18%). More positively, over half of carers felt recognised, respected and valued by care workers and service providers.
- Young carers experience high levels of stigma and judgement. They said they need more understanding from the community.
- Many carers feel excluded by services and that their views are not considered. Carers of people with mental illness shared their experiences of being excluded from psychologist and psychiatrist appointments, and not being given information about diagnoses.
- Young carers do not feel recognised or respected by professionals (eg NDIS planners, health services), and often feel undermined when reporting issues for the person they are caring for.
- Carers are rarely asked by service providers about their wellbeing and what support they need in their caring role.



## What carers told us would help them

- Carers told us that they may not relate to a 'carer strategy' if they do not identify as a carer. They suggested that we call it a 'caring strategy' because 'caring' is what carers do.
- Carers want to be recognised as partners in care. They want to be included in assessments, planning, discharge, appointments and given more information.
- Aboriginal carers told us that culture should be respected and better understood.
- Aboriginal carers also suggested community campaigns could help to address the stigma associated with being a carer. Carer champions or ambassadors may be an effective way to share information about caring, build knowledge at the community level, break down stigma, and build the resilience and strength of carers.
- Media could play a greater role in focusing on carer strengths and educating the community, rather than focussing on negative stories.
- Carers want to feel empowered to enact their rights and access the supports they need.
- Young carers want communication in the media and education around the characteristics of different disabilities and the impact of disabilities on the family.
- Carers want more inclusive community activities and facilities, so they can participate alongside the person they care for.
- There is a need for cultural awareness training to ensure Aboriginal and CALD carers are being treated with respect by mainstream workers
- Carers want service providers and professionals (particularly GPs, psychiatrists, hospitals, neurologists, teachers and principals) to be trained and educated about the role of carers, their rights, and the benefits of including carers as partners in care.



**Doctors have absolutely no idea of the role carers play and when you raise the issue you are quickly handed a pamphlet or given a phone number to call rather than listened to with a real issue.**

**Carer at co-design workshop — 2019**

## What we know

- The 2018 Carers NSW Survey found only one in four carers felt their caring role was recognised by their community despite the Carers (Recognition) Act being introduced in 2010. This finding indicates that we have considerable work to do to improve carer recognition in NSW<sup>9</sup>.
- Many carers were able to disclose their caring role at work and utilise flexible working arrangements. However, many carers also said their caring responsibilities interfered with paid work. Some carers had to reduce their working hours or cease work due to their caring role impacting their economic status<sup>10</sup>.
- Many Aboriginal carers do not identify as a carer and therefore do not access information or support. For example, there is no equivalent word for 'disability' in many Aboriginal and Torres Strait Islander languages. This may contribute to under-reporting of disability and underutilisation of disability services<sup>11</sup>.
- People from CALD backgrounds are under-represented in the disability service system in Australia<sup>12</sup>. In addition, CALD carers face a number of unique barriers to accessing services. CALD carers may be particularly reluctant to use residential care<sup>13</sup>, due to safety and cultural reasons, such as a preference to keep relatives at home. In addition, mainstream disability organisations may lack culturally competent staff who can deliver culturally responsive supports<sup>14</sup>.
- CALD carers may also have difficulty understanding eligibility requirements, navigating the service system and accessing information.<sup>15,16,17</sup>
- Evidence suggests involving consumers and their carers in decision making about their individual care leads to better health outcomes.<sup>18</sup>
- Research shows that carers of people with a mental illness experience less stress if they are involved in the treatment and support of the person they care for.<sup>19</sup>
- The 2018 Carers NSW Survey found that the majority of carers were included in decision making by GPs (85%) and at hospitals (78%). However, very few carers reported being asked about their needs as a carer.<sup>20</sup>





## Carers have improved financial wellbeing and economic opportunities

“

*(Regarding not being told that financial help was available)* **This should happen upon diagnosis. Doctor should report information to Medicare who then should pass on information directly to NDIS and Centrelink. After all, aren't all these government organisations supposed to be linked? It took the pharmacy lady to tell me to ask for a health care card for my son.**

“

**No one really understands what it's like to live this life. It's constant stress, pressure and financial horror.**

“

**Government has not respected the role of carers and work doesn't respect the role of carers. Carers have little superannuation.**

## What carers told us

- Overwhelmingly, carers told us they are stressed about their finances and need greater financial assistance. In our online survey, carers told us they were most concerned about planning for the future (38%) and finances (37%). Female respondents were more concerned than male carers about planning for the future (37% versus 32%) and employment (33% versus 26%).
- Financial stress was also consistently raised at our workshops. Feedback indicates this is worsening due to service reforms and impact of other pressures, such as drought in rural/regional areas.
- There are significant costs associated with caring, including transport, medical costs and loss of income. Carers told us they often have to fund supports themselves, as they are not covered by the health system, aged care or NDIS. They told us the Carer Payment/Carer Allowance is insufficient to cover these costs.
- Carers are concerned for their financial future. Many carers have reduced or ceased paid work to provide care, and this affects their superannuation. Young carers may be significantly financially impacted by caring responsibilities as this happens earlier in their lives.
- Many people with caring responsibilities do not identify as carers. As a result, these carers may not be receiving their full financial entitlements. This is particularly the case for Aboriginal and CALD carers.
- Some carers do not feel respected, recognised or valued at work. In our online survey, carers reported difficulty taking leave from work to accommodate their caring responsibilities.
- To remain eligible for the Carer Payment, carers must limit the number of hours they work or study. Carers told us this negatively affects their work and study.

“

**Many employers don't value carers... It's hard to negotiate flexible hours ... I do feel isolated as not many social groups out there. There isn't any planning help for me for the future as I'm busy taking care of my mum and I'm sole carer for her.**

Carer at co-design  
workshop — 2019



Carer presenting at a carer co-design workshop - Parramatta 2019

## What carers told us would help them

- Increased assistance to access basic payments through Centrelink and other financial entitlements and rebates.
- Help with financial literacy and planning for the future.
- Financial subsidies for carers to access community activities eg young carers who want to learn how to drive, discounts for carers similar to the Seniors Card.
- Financial assistance to meet the additional costs associated with caring, for example costs of transport and medical expenses.
- Improved support for carers to balance caring and work and to build a career.
- Support for young carers to reach their potential in education both at school and in their transition to further education, training or employment.

## What we know

- In 2018, the weekly median income of primary carers was \$621, compared to \$997 for non-carers<sup>21</sup>. Approximately 40%<sup>22</sup> of primary carers are on a low income, and many find it hard to cover living expenses, save money or build up superannuation.
- Taking on caring responsibilities significantly affects an individual's ability to work. Many carers leave paid employment, either permanently or on a part-time basis, to become carers. This also limits their capacity to build superannuation. In addition, carers have high household expenditure levels relative to their income, due to the additional costs of caring such as laundry, medicines, disability aids, health care, transport, heating and laundry. As a result, there is little opportunity for household savings.<sup>23</sup>
- The structure of benefits can mean that working or working longer hours, can leave carers worse off.<sup>24</sup>
- Carers can find it hard to manage their caring responsibilities while rigidly tied to when, where or how they work. Flexible working arrangements are therefore critical to balancing care and work successfully.
- Carers are also much more likely to live in poverty in their old age. Female primary carers aged 30-64 years of age have markedly lower rates of paid workforce participation than other women in the same age group.<sup>25</sup> This leads to higher levels of financial stress and reduced ability to build superannuation. This is of particular concern given that female carers are more likely to retire early.<sup>26</sup>
- Barriers to accessing transport directly affects carers access to services and supports. A study by Carers South Australia, found 67% of respondents had missed appointments or activities due to transport issues.<sup>27</sup>
- Transport is particularly challenging for carers in rural and remote areas. Carers often have to wait long periods for transport services and must travel considerable distances to access support services.<sup>28</sup> Issues with transport can lead to delays in medical treatment or support, which can compound medical problems, and which can increase the burden on carers.<sup>29</sup> Indigenous carers in both rural and urban areas, consistently report transport as a main barrier to accessing services.<sup>30</sup>



## Carers have better health and wellbeing

“

I am absolutely terrified about our future. I work from home (own business) but can only work so much due to my husband's high needs. I fear for our future and what that entails, I fear for our life when our daughter leaves home (she's 16) because she's a HUGE help. I fear for my own health and mental health. Being a carer of a quadriplegic is not an easy road, and it's not a road I chose. He was injured 12 years ago and it can be terrifying.

“

It's a challenge to get counselling that is ongoing. I have a patchwork of phone counselling and face-to-face. It is expensive and mental health plan provides only 12 sessions per year.

## What carers told us

- Carers told us they are very aware of the negative impact of caring on their own health and wellbeing, but find it difficult to prioritise themselves.
- Carers experience a range of health issues that affect their wellbeing. This includes stress, anxiety, lack of sleep, obesity, poor diet and limited exercise.
- Many carers were concerned about burnout. They told us they need strategies to cope and more supports to improve their mental health. They feel lonely and isolated, and want opportunities to build social connections, particularly with other carers who share their experience.

“

**As a carer, you are caring for someone 24/7, because there is not enough respite care out there only 63 days annually. Add up a carers role, 8hrs a day 365 days a year. No wonder we get burnt out...**

Carer at co-design workshop — 2019

## What carers told us would help them

- Overwhelmingly, carers told us they need a break from their caring role so they have more time to look after themselves. They want greater access to respite, carer retreats, peer support and support groups, and practical support at home.
- Carers want cheaper and more accessible physical exercise, nutrition advice and assistance with meals and cooking.
- Carers want health services to focus on earlier intervention and their physical and mental health (eg carer health checks and Aboriginal women's health days).
- Carers want education, training, counselling and psychological interventions to help them manage stress and address mental health issues.
- Carers want reduced barriers to accessing services including waiting lists, costs and transport.

“

**There is nothing better than talking to another carer.**

**(Respite) made me feel supported, valued, important, cared for.**

Carer at co-design workshop — 2019



# What we know

- We know from research that carers have low levels of physical health, mental health and wellbeing.
- A survey conducted by Carers NSW in 2018 found that carers reported the lowest level of wellbeing for the domains of health, achieving in life and future security.
- Carers are more likely than non-carers to experience higher levels of stress, poorer health, and increased risk of using unhealthy behaviours to cope with stress.<sup>31</sup>
- Australian data shows that female carers have on average lower levels of wellbeing than male carers. Caring for adults is less stressful than caring for children, but caring for adult children imposes a heavier burden than caring for a spouse.<sup>32</sup>
- Pursuing meaningful leisure activities improves mental and physical wellbeing. In one study, carers reported that the key negative consequence of caring was the inability to pursue leisure activities.<sup>33</sup>
- In Australia, carers' mental health declined over time if they cared for long hours. Women who combine high levels of care (over 20 hours per week) with employment experienced a significant decline in their mental health over two years. Men with high levels of care experienced significant mental health declines after four years.<sup>34</sup>
- The carers at greater risk of poor wellbeing include:
  - carers with a long-term illness or disability themselves
  - carers who have been caring longer
  - carers providing more hours of care per week
  - female carers
  - younger carers
  - carers receiving government financial assistance
  - Aboriginal and Torres Strait Islander carers
  - carers living outside of greater Sydney.<sup>35</sup>
- Carers report the need for more information and accessible, affordable services providing practical and emotional support<sup>36</sup>.
- Research suggests carers need support that is flexible and tailored to their specific needs. Carers also need a combination of different supports, including:
  - respite care/replacement care
  - education and training and psychoeducation
  - counselling/psychosocial interventions/therapy
  - support groups
  - practical help in the home
  - physical exercise
  - technological interventions<sup>37</sup>.
- Some barriers for carers in taking a break from caring include availability of services in rural and regional areas, access to appropriate psychological support, access to practical support in the home and access to respite for carers.<sup>38</sup>

Carer co-design workshop  
Sydney CBD 2019



# Co-design methodology

The methodology we have adopted places carers firmly at the centre of the co-design process and was approved by the Carers Strategy 2020 Program Management Group (PMG) in July 2019.

The Program Management Group comprised carers and representatives from:

- NSW Carers Advisory Council
- Carers NSW
- Mental Health Commission of NSW
- Mental Health Carers NSW
- academia from University of New South Wales
- CALD and Aboriginal communities
- NSW and Commonwealth Government (DCJ, NSW Health, NSW Department of Education, Women NSW, Commonwealth Department of Social Services)
- non government organisations (Plumtree and Dementia Australia NSW)

A two stage co-design process to identify diverse carers' needs, priorities and possible solutions commenced in March 2019 and was completed in February 2020. The NSW Carers Advisory Council and the NSW Disability Council were consulted throughout the co-design process.



Aboriginal carer co-design workshop - Dubbo 2019



# Co-Design Summary



Developing the NSW Carers Strategy through a co-design process.

## WE TALKED TO PEOPLE ABOUT



Access to services and support



Health and wellbeing



Information



Recognition and respect

## CO-DESIGN PROCESS SUPPORTED BY



Program Management Group (PMG) including carers, state and Commonwealth Govt, NGO's and academia



NSW and Commonwealth Government



NSW Carers Advisory Council



Aboriginal Working Group

## STAGE ONE

### 10 Face-to-Face Workshops

LOCATIONS:

Dubbo

Sydney

Wollongong



CONDUCTED OVER:

8 August - 15 November 2019

& 1 Online Survey



### 404 Participants & Respondents

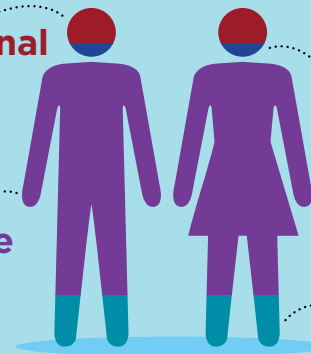
There was a broad cohort of carers involved, including:

Aboriginal Carers

Young Carers

Female Carers

CALD



## STAGE TWO

1.

Analysed, refined and tested the **key carer themes and priorities**



2.

Engaged with individual stakeholder agencies to **draft possible solutions**



3.

First 2 year **action plan developed**



## NEXT STEPS



**Implement the strategy and action plan**



### Stage One – February - November 2019

- *PMG Governance Group* – ongoing consultation and engagement with the PMG to provide advice and identify key themes and issues for carers
- *NSW Carers Advisory Council* – regular consultation with council members on the co-design approach, vision, draft priorities
- *face-to-face co-design workshops* – held from 8 August 2019 - 15 November 2019 to test key themes with carers and key stakeholders, identify carers needs and priorities and co-design solutions
- *carer conversation kits* – to help interested carers and stakeholders to facilitate local conversations, with questions that mirrored those covered in the face-to-face workshops
- *online carer survey* – for individual carers to provide input into the key themes and priorities.

### Stage Two – December 2019 - March 2020

- analyse and refine the key carer themes and priorities identified through Stage One. The key themes were tested with co-design workshop participants, Strategy PMG, NSW Carers Advisory Council and NSW Disability Council
- engage with individual stakeholder agencies to draft possible solutions in response to carer priorities, including consideration of project origin, scope, feasibility, evidence, reach and availability of resources
- some of these solutions now appear as actions in the First Two Year Action Plan 2020-2022. Solutions not included in the first action plan will inform the development of future action plans.



Aboriginal carer presenting at Aboriginal carer co-design workshop Blacktown 2019



# Carer co-design workshops

From 8 August to 15 November 2019 DCJ (supported by PWC and Origin Communications) ran ten face-to-face workshops in a range of locations across NSW. We ran six workshops in Sydney Metro Area and four in regional centres. The workshops aimed to identify carers needs and priorities and possible solutions. We held a mix of generic and targeted workshops, including specific workshops for Aboriginal carers, CALD carers and young carers. In all workshops, we aimed to include carers with a wide range of caring experiences.

This included:

- carers of people with disability
- carers of people with mental illness
- carers of people with drug and alcohol issues
- carers of people who are frail-aged
- carers of people with dementia
- carers of people with chronic illness
- young carers
- older carers
- people from CALD backgrounds
- Aboriginal people

- LGBTQI community
- veterans who are carers and carers of veterans
- carers living in metro areas
- carers living in rural, regional or remote areas
- government agencies
- non-government organisations
- private organisations, academia

See Table 1 for breakdown of locations and participants.

Confirming that carers were at the centre of this process, almost half of the workshop participants were carers (49%).

The workshops focused on four key themes :

- access to services and supports
- health and wellbeing
- information and resources
- carer recognition and respect.



Young carer co-design workshop UTS 2019



**Table 1: Summary of locations and participants in the co-design workshops**

<b>Workshop</b>	<b>Total Participants</b>	<b>Aboriginal people</b>	<b>CALD</b>	<b>Female</b>	<b>Young carers</b>
1. Blacktown	28	19	0	24	0
2. Parramatta	27	1	9	18	0
3. Wollongong	30	0	26	28	0
4. Sydney CBD	36	0	6	30	2
5. Dubbo	22	16	0	19	0
6. Dubbo YC	3	0	0	0	3
7. Dubbo	13	1	0	11	0
8. Carers Investment Program (CIP) workshop	15	4	1	11	0
9. Dementia carers – Sydney	20	0	4	06	3
10. Young carers – UTS Sydney	10	0	5	04	7
<b>TOTAL</b>	<b>204</b>	<b>41</b>	<b>51</b>	<b>151</b>	<b>15</b>

An additional three carer workshops/small group sessions were conducted by our partners and individuals using the Carer Conversations Kits. These smaller workshops were with Aboriginal carers, carers of people with dementia and carers of people with mental illness. The dementia workshop facilitated by Dementia Australia (and attended by DCJ) is also listed in the table above.

## Online survey for carers

We conducted an online survey to give carers greater opportunity to participate in the co-design process. The survey was available via the DCJ website and distributed widely through carer and stakeholder networks. The survey asked carers questions around the four key themes discussed in the co-design workshops.

200 carers responded to the survey. The majority of respondents (84%) were female, older carers (over half between 56 and 75 years). They care for people with a range of conditions including:

- disability (56%)
- mental illness (51%)

- chronic illness (24%)
- aged-related need (26%)
- dementia (15%)
- drug and alcohol issues (7%).

The sample was representative of the NSW population, with:

- 5% of respondents from an Aboriginal or Torres Strait Islander background
- 29% of respondents CALD carers and speak a language other than English at home
- 70% of respondents living in an outer Sydney/regional or rural remote location.

**Table 2: Summary of respondents to NSW Carers Strategy online survey**

Carer Strategy online survey	Total Participants	Aboriginal people	CALD	Female	Young carers	Non-Metro
Total number of participants	200	10	59	171	3	144
<b>PERCENT</b>		<b>5</b>	<b>29</b>	<b>84</b>	<b>2</b>	<b>70</b>

## Future co-design work

We will continue to use a co-design approach to implement the Strategy over the next ten years, including developing the action plans. We will use a strengths-based and culturally appropriate methodologies to design and implement projects.



Carer workshop - Sydney CBD 2019

# References

- 1 Hill et al., *Carers and Social Inclusion: New Frameworks, Evidence and Policy Lessons*.
- 2 Mind the Gap: The National Disability Insurance Scheme and psychosocial disability Final Report: Stakeholder identified gaps and solutions January 30th, 2018
- 3 Australian Institute of Health and Welfare, *Australia's Welfare*, Sept 2019
- 4 2014 Carers NSW survey 40 Years of Caring 1976 – 2016 p11
- 5 2018 Carers NSW Survey Summary Report p21
- 6 Hill, T., Broady, T. (2019). *Understanding the social and emotional needs of carers: Final report (SPRC Report 2/19)*. Sydney: Social Policy Research Centre, UNSW Sydney
- 7 2018 Visa, B and Harvey C *Mental health carers' experiences of an Australian Carer Peer Support program: Tailoring support to carers' needs*.
- 8 2018 Visa, B and Harvey C *Mental health carers' experiences of an Australian Carer Peer Support program: Tailoring support to carers' needs*.
- 9 2018 Carers NSW Survey Summary Report p32
- 10 2018 Carers NSW Survey Summary Report p32
- 11 *Australian Human Rights Commission's Social Justice and Native Title Report 2015*
- 12 Future Ability - Multicultural Communities Getting NDIS Ready Project Report 2016, Settlement Services international
- 13 Shanley, C., Boughtwood, D., Adams, J., Santalucia, Y., Kyriazopoulos, H., Pond, D., et al. (2012). A qualitative study into the use of formal services for dementia by carers from culturally and linguistically diverse (CALD) communities. *BMC Health Services Research*, 12, 354-354.
- 14 Future Ability - Multicultural Communities Getting NDIS Ready Project Report 2016, Settlement Services international
- 15 Caroline Riches article *Newer Australians missing out on NDIS assistance*, Community Care Review, 27 Feb 2019
- 16 Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature. *Health & Social Care in the Community*, 23(1), 64-78
- 17 Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature. *Health & Social Care in the Community*, 23(1), 64-78
- 18 Gordon S (2005) The role of the consumer in the leadership and management of mental health services. *Australasian Psychiatry*, 13(4): 362-365
- 19 Cuijpers P (1999) The effects of family interventions on relatives' burden: a meta-analysis. *Journal of Mental Health*, 8(3): 275-85
- 20 2018 Carers NSW Survey Summary Report p20
- 21 Australian Bureau of Statistics.4430.0 Disability, Ageing and Carers Australia: Summary of Findings 2018 Released 24/10/2019

- 22 Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers
- 23 Commonwealth Financial planning – Women Carers in Financial Stress Report, Lifetime health and economic consequences of caring: modelling health and economic prospects of female carers in Australia, The National Centre for Social and Economic Modelling, University of Canberra, 2008
- 24 [https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/581/58104.htm#\\_idTextAnchor005](https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/581/58104.htm#_idTextAnchor005)
- 25 Binod Nepal, Laurie Brown, Geetha Ranmuthugala and Richard Percival, Women Carers in Financial Stress – Lifetime Health and Economic Consequences of Caring: Modelling Health and Economic Prospects of Female Carers in Australia (2009) pp 1-2. Available at <http://www.carersaustralia.com.au/?/national/article/view/623> (viewed 2 September 2009).
- 26 Australian Industry Group ‘Skills and Mature Age Workers: Final Report’ (undated) p 50.
- 27 Carers SA Transport and Care Survey Summary Report - Dec 2018 pg 4
- 28 Challenges in providing end-of-life care for people with intellectual disability: Health services access. Wark S, Hussain R, Müller A, Ryan P, Parmenter T J Appl Res Intellect Disabil. 2017 Nov; 30(6):1151-1159.
- 29 Caregiving, Employment and Social Isolation: Challenges for Rural Carers in Australia, Rafat Hussain, Stuart Wark, and Peta Ryan, Int J Environ Res Public Health. 2018 Oct; 15(10): 2267.
- 30 [https://www.dss.gov.au/sites/default/files/documents/12\\_2013/sprp45\\_dec2013\\_web\\_4.pdf](https://www.dss.gov.au/sites/default/files/documents/12_2013/sprp45_dec2013_web_4.pdf)
- 31 L L. Bedini, JD. Labban, NJ. Gladwell, & W N. Dudley, The Effects of Leisure on Stress and Health of Family Caregivers, *International Journal of Stress Management* 2018, Vol 25, Supplement 1, 43-55
- 32 Cummins, Hughes etc al (2007) cited in Woods, R. and McCormick, S., 2018, *Carer Wellbeing and Supports: A review of the literature and directions for research*, Centre for Carers Research, Institute of Public Policy and Governance, University of Technology Sydney.
- 33 L L. Bedini, JD. Labban, NJ. Gladwell, & W N. Dudley, The Effects of Leisure on Stress and Health of Family Caregivers, *International Journal of Stress Management* 2018, Vol 25, Supplement 1, 43-55
- 34 T. Hill and T. Broady (2019). Understanding the social and emotional needs of carers: Final Report
- 35 L L. Bedini, JD. Labban, NJ. Gladwell, & W N. Dudley, The Effects of Leisure on Stress and Health of Family Caregivers, *International Journal of Stress Management* 2018, Vol 25, Supplement 1, 43-55
- 36 T. Hill and T. Broady (2019). Understanding the social and emotional needs of carers: Final Report
- 37 T. Hill and T. Broady (2019). Understanding the social and emotional needs of carers: Final Report
- 38 Carer case studies, NSW Carers Advisory Council



Aboriginal carer co-design workshop – Dubbo 2019