



NSW CARERS STRATEGY 2014-2019

PROGRESS REPORT



OCTOBER 2016



Contents

Foreword	4
Executive Summary	6
NSW Carers Strategy 2014-2019 at a glance	7
Introduction	8
Focus area 1: Employment and education	10
Summary of progress	10
Highlight report – Project 1.2 Recognising carers' skills	11
Focus area 2: Carer health and wellbeing	14
Summary of progress	14
Highlight report - Project 2.1 Easier access to health care	14
Focus area 3: Information and community awareness	17
Summary of progress	17
Highlight reports -	17
Project 3.1 Media campaigns to raise the profile of carers	18
Project 3.2 Embed and improve information for carers	20
Project 3.3 Young carer mobile application (app)	22
Project 3.4 Information for carers in Aboriginal communities	24
Focus area 4: Carer engagement	28
Summary of progress	28
Highlight report – Project 4.2 Partners in care (communitary service delivery)	28
Focus area 5: Improving the evidence base	31
Summary of progress	31
Project 5.1 Using the evidence base about carers	31
Governance and reporting	32
Next steps	33
Acknowledgements	33
Appendix A - NSW Carers Strategy 2014-2019 Monitoring & Evaluation Program Logic	34
Appendix B - Update on NSW Carer Strategy projects	36

Foreword



Every day, in homes around NSW, more than 857,000 ordinary people do extraordinary things. These selfless individuals help their loved ones live better, richer and more independent lives by giving unpaid care and support.

However, caring can at times be difficult and challenging. Having spoken to carers right across NSW, I know it can take a toll, especially when they don't have the information or support they need.

The NSW Government gets it. That is why we developed and delivered the NSW Carers Strategy 2014-2019. We want carers to be supported in participating in all aspects of social and economic life, to be healthy and to live well.

We don't want carers to have to choose between caring and finishing school. We don't want carers to have to choose between caring and getting a job.

This Report details the significant progress that has been made in the two years since I launched the Strategy.

Importantly, the NSW Government's commitment to carers doesn't end with the Strategy. At present, we are reviewing the *NSW Carers (Recognition) Act 2010* to ensure we are recognising carers and their immense contribution in the best ways possible.

What's more, the NSW Government is successfully implementing the National Disability Insurance Scheme (NDIS). The NDIS is already changing the lives of many carers in NSW. I am working closely with my partners in reform to ensure the Scheme delivers for carers, as well as for the people they support.

Thank you to all of our partners for their hard work and commitment over the past two years.

I am proud of our progress and eager to do even more for our carers.

A handwritten signature in black ink that reads "John Ajaka".

The Hon. John Ajaka MLC

Minister for Ageing
Minister for Disability Services



Executive Summary

The Carers Strategy 2014-2019 is a whole-of-government and whole-of-community response to support carers in NSW. As well as delivering on specific projects, the role of the Strategy has also been to influence the wider carer agenda.

This report outlines progress made in the first two years of the five year plan. The strong partnerships and collaborations formed during development of the Strategy have continued into the implementation phase. Co-design with carers and other key partners continues.

The Department of Family and Community Services (FACS) has established the Carers Strategy Implementation Committee. Implementation Committee members include representatives of organisations involved in Strategy projects and carer representatives. The Committee oversees the implementation of the Strategy including the specific projects, the longer term reform directions, and monitoring and evaluation. The Implementation Committee developed the Monitoring & Evaluation Program Logic (at **Appendix A**).

This Progress Report highlights in detail seven projects that have made significant progress. The diagram on the following page (NSW Carers Strategy 2014-2019 at a glance) is reproduced from the Strategy, and captures the vision and the reform directions and outcomes under the five focus areas.

All three projects in Focus Area Three are highlighted in the Report, reflecting the priority carers place on the need for better information and community understanding.

Data being collected to measure the success of the Strategy projects will provide a platform to build an evidence base for carers (Focus Area Five).

A more detailed progress report on the work underway on Focus Area Five will be highlighted in a future report.

Implementation of the Strategy will continue with a greater focus on the projects that are in their early stages.



NSW Carers Strategy 2014-2019 at a glance

Vision

- Carers and caring are respected and valued
- Carers have the time and energy to care for themselves
- Carers have the same rights, choices and opportunities as other members of the community

Focus areas	Planned reforms	Expected outcomes
1 Employment & education	<ul style="list-style-type: none"> • Increase the use of existing workplace flexibility by carers and their employers • Enable carers to recognise the skills and expertise they bring to employment and training • More young carers receive support at school to transition to further education and employment 	<p>Carers have choices and opportunities to participate in paid work</p> <p>Young carers complete school and transition to further education and employment</p>
2 Carer health & wellbeing	<ul style="list-style-type: none"> • Improve the design and delivery of services and programs in ways that make it easier for carers to look after their own health and wellbeing 	<p>Carers experience good health and wellbeing</p>
3 Information & community awareness	<ul style="list-style-type: none"> • Embed and improve information for carers in the trusted systems they frequently use • Create positive media campaigns that portray carers as real people • Increase the number of people with an understanding of carers lives 	<p>Carers are able to easily access information when they need it</p> <p>Carers feel the broader community understands their experience</p>
4 Carer engagement	<ul style="list-style-type: none"> • Continue to improve the ways we involve carers as partners in the care delivered to their loved ones • Greater involvement of carers in local decisions about the design and delivery of services 	<p>Carers are involved in decisions that affect them and the people they care for</p>
5 Evidence base	<ul style="list-style-type: none"> • Better use is made of the available data and research to create evidence that will shape policy and programs 	<p>Carers policy and practice is informed by quality evidence</p>

Principles

- The Strategy will be implemented in collaboration with carers, the private sector, non-government organisations and governments to achieve better and enduring outcomes for carers.
- Projects will support the diversity of carers including those from culturally and linguistically diverse backgrounds, Aboriginal carers and young carers.
- The Strategy is a living document that will provide a platform for further work.

Introduction

The Strategy includes 16 projects that will make a practical difference for carers in the following focus areas:

1. Employment and education
2. Carer health and wellbeing
3. Information and community awareness
4. Carer engagement
5. Improving the evidence base.

Partnerships with key stakeholders have been central to the implementation of the Strategy. As a result, in addition to providing their support for Strategy projects, our stakeholders are champions for carers in their own networks and spheres of influence. This is evidenced by testimonials featured in this report and examples of increased awareness and responsiveness to the needs of carers such as a new question about caring responsibilities which was included in the NSW Public Service Commission's 2016 *People Matter Employee Survey*.

Seven Strategy projects have been highlighted in this report because they are either completed or have made significant progress. These projects are:

- 1.2 Recognising carers' skills
- 2.1 Easier access to health care
- 3.1 Media campaigns to raise the profile of carers
- 3.2 Embed and improve information for carers
- 3.3 Young carer mobile application (app)
- 3.4 Information for carers in Aboriginal communities
- 4.2 Partners in care (community service delivery).

Future progress reports will highlight other Strategy projects. **Appendix B** provides an update on all 16 Strategy projects.

The Program Logic at **Appendix A** shows how data collected from the projects will be used to measure the achievement of Strategy outputs and outcomes.

"We appreciated the opportunity to be involved and to facilitate local carers' voices being heard"

"I was able to contribute my own lived experience as a carer towards the co-design process and increase knowledge and understanding about carer issues to other participants/corporations involved"

Co-design participants, 2016

Baseline performance data is being gathered, and qualitative data will be collected, for example through focus groups, interviews and case studies, to measure and monitor the outputs and outcomes of the projects.

Relevant population level data and larger data sets and surveys will be analysed in relation to what they show about outcomes for carers in the areas the Strategy is trying to influence.

Identification of appropriate data and evidence about carers, and data gaps, will be a continuing focus of work for all the Strategy projects, and will be drawn together under project 5.1.

“Carers should be central to the work of all agencies and organisations that provide services to people who experience mental illness. A cultural shift is required to ensure carers feel more valued and included, along with people living with a mental illness. The Carers Strategy progress report illustrates projects that aim to address this shift and rebalance the system to provide carers with the respect and opportunities that they deserve. I commend the Department of Family and Community Services for leading this important work.”

John Feneley, NSW Mental Health Commissioner, July 2016

Focus area 1: Employment and education

Expected outcomes in the Strategy

Carers have choices and opportunities to participate in paid work

Young carers complete school and transition to further education and employment

Summary of progress

Carers have said that combining caring and paid work is one of their highest priorities, but that being out of the workforce made it hard for them to understand how the skills they developed as a carer could be valuable to an employer. Young carers have said finishing school is critical to them attaining higher education and/or employment opportunities.

There are five Strategy projects in this focus area:

- 1.1 Network of employers to champion carer friendly workplaces
- 1.2 Recognising carers' skills
- 1.3 Carers working in the NSW Government sector
- 1.4 Support for carers at school
- 1.5 Young carer mentoring.

Strong progress has been made in improving outcomes for carers in this focus area. All projects have commenced and together they will support carers to combine paid work and caring and support more young carers to remain at school.



Highlight project 1.2 Recognising carers' skills

Lead agency

NSW Community Services and Health Industry Training Advisory Body (NSW CSH ITAB) with the Department of Family and Community Services (FACS).

Identified need

It can be hard for carers to explain to potential employers how the time they spent caring (sometimes many years) translates into employable skills, especially in professions outside paid caring roles.

Project description

This project aimed to develop an interactive online resource to assist carers to understand how the skills, knowledge and experience they have acquired as carers can be translated into 'employable' skills.

Progress to date

A partnership was formed with the Commonwealth Department of Social Services to support employment projects for carers. The NSW Community Services and Health Industry Training Advisory Body worked in a co-design approach with carers, FACS, the Department of Social Services, Carers NSW and Disability & Aged Information Service Inc (DAISI) Ballina NSW.

Extensive consultation occurred with carers across NSW who helped develop the website's list of skills and test the website. Sixty carers attended five focus groups during May 2015 in Dubbo, Ballina, Kanwal, Sutherland and Wollongong.

SkillsLink2Work, an interactive online resource to match carer skills to employment, was jointly launched on 29 April 2016 by the Hon. John Ajaka MLC, NSW Minister for Disability Services and Minister for Ageing and the Hon. Jane Prentice MP, Commonwealth Assistant Minister for Disability Services.

Key achievements

- Developed the *SkillsLink2Work* website, a free resource available at www.skillslink2work.com.au and a Communications Toolkit to support the promotion of the website.
- A partnership with the Australian Government was formed, which resulted in the development of a new interactive website that helps carers to apply for paid work and training.



Next steps

- Ongoing monitoring of carers' use of *SkillsLink2Work* will continue as well as contacting carers for feedback about their experience using the site.
- During development of the website, some carers advised that they needed help to develop a resume. The website has potential to be further developed to help carers with this and other aspects of looking for employment.

"A good confidence booster. I CAN do all that!"

"It is a tool that will empower their self esteem."

Feedback from *SkillsLink2Work* user testers



START HERE



TOUR



MY SKILLS



MY REPORTS



MY SETTINGS



SkillsLink2Work



Australian Government



SkillsLink2Work is funded by the NSW Department of Family and Community Services and the Commonwealth Government Department of Social Services.

SkillsLink2Work Case story: Meet Dolly, a proud Dungutti woman from the far north coast

As one of 16 children I'm from a big family where caring happens naturally in my immediate family and throughout my community.



I care for my grown up daughter who has a disability but I'm also naturally linked to my community. When I was working I had a supportive manager but I was having difficulty accessing services for my daughter so I thought about my options and decided to become her full time carer. I've now been a full time carer for several years. By being there for her she has built up some strength and confidence so it's the right time to start thinking about me to be employed again.

When I heard about *SkillsLink2Work* I saw it as a stepping stone to create a place for myself to get back into the workforce. The skills lists are easy to understand and help me think about everything I do as a carer. The website took me through in a positive way. There's no real age barrier in getting employment and *SkillsLink2Work* shows me I can achieve. I can get a job.

Focus area 2: Carer health and wellbeing

Expected outcome in the Strategy

Carers experience good health and wellbeing

Summary of progress

Carers have said that it can be difficult to find the time, energy and resources to look after themselves. Carers are less likely to use services if they face long queues, complex processes and non-negotiable start and finish times. Many carers are unable to use services if there is no one to assist with those they care for.

There are three Strategy projects in this focus area:

- 2.1 Easier access to health care
- 2.2 Individualising respite and support services
- 2.3 Carer peer support.

Highlight Project 2.1 Easier access to health care

Lead agency

NSW Health with Carers NSW, the Department of Family and Community Services (FACS) and Healthdirect Australia

Identified need

Carers are a vulnerable ‘at risk’ group in terms of their own health and wellbeing. Carers have the lowest wellbeing of any large group as measured by the Australian Unity Wellbeing Index¹. Carers are 40 per cent more likely to suffer from a chronic health condition. Health issues like back problems, anxiety and depression, can also be directly linked to caring². Carers are more likely to report high blood pressure (41.6 per cent), high cholesterol (28.8 per cent), and being overweight or obese (55.7 per cent) compared to non-carers³.

Project description

This project aimed to bring together a number of different NSW Health initiatives to ensure health care services are accessible to carers.

¹ Australian Unity Wellbeing Index, Survey 17.1, Report 17.1, page 6, 2007

² The Health and Wellbeing of Adult Family Carers in South Australia 1994 – 2004, page 14, 2007

³ Ibid.

Progress to date

The project built links across the public health system with key partners across a number of different initiatives:

- *NSW Family and Carer Mental Health Program* adapted so that support and training about mental illness and management for families and carers is carer-friendly and responds to the needs of specific carer groups such as culturally diverse populations, Aboriginal people and those living in rural and remote locations.
- *After-Hours Palliative Care Helpline* adapted to provide advice and psychosocial support to carers of people who have a life-limiting illness in the after-hours period.
- *Last-Days-of-Life Home Support Service* developed to provide palliative care support for carers who are taking care of patients at their end of life who wish to remain or die at home.

The project also ensured that carers' needs are considered in the following broader health initiatives:

- *Online training* developed, in partnership with the Health Education and Training Institute, for staff across the NSW Health system to increase the awareness of carers and their role.
- *Carer support positions* across Local Health Districts maintained to continue to build capacity of the public health system to be responsive to the needs of carers.
- The *Get Healthy Information and Coaching Service* promoted to carers and to health coaches, to not only be aware of the needs and challenges experienced by carers but also to tailor their approach to individual carers.
- *Stepping On*, a falls prevention program, adapted and actively promoted to carers and carer organisations to increase access by carers.

Key achievements

- Extensive network of carer support staff across Local Health Districts (approximately 20 Full Time Equivalent).
- Approximately 800 staff across NSW Health have completed the NSW Health Education and Training Institute online education module *Partnering with Carers*.
- Over 10,000 health promotion resources for the *Get Healthy Information and Coaching Service* have been disseminated by NSW Health staff.
- Over 4,400 packages of the *Last-Days-of-Life Home Support Service* have been delivered throughout NSW since December 2013.



Next steps

Future work will focus on ensuring the health and wellbeing needs of carers continue to be integrated across the primary and acute health care setting. NSW Health will work with pharmacies to promote the health and wellbeing of carers and will also ensure that the needs of carers are reflected in actions that promote disability inclusion across the NSW health system.

"I've cared for my wife for 9 years. It's been interesting being on the caring journey. I've seen a whole lot of recovery but there have also been struggles to get the right information and service and get through a wall of secrecy. I share this information with other carers as soon as I get it.

Through the Family and Carer Mental Health Program I have received valuable education, training and support from an individual support worker. The Program has given me skills and resilience and also helped me to understand the health system and how it works."

Carer receiving support through the NSW Health Family and Carer Mental Health Program



Focus area 3: Information and community awareness

Expected outcomes in the Strategy

Carers are able to easily access information when they need it

Carers feel the broader community understands their experience

Summary of progress

Feedback from carers indicates that this focus area was one of their highest priorities and that access to good information underpins their ability to provide care. Carers have said that finding information is too time consuming.

Carers also said that among the broader community there is a lack of understanding about carers and what they do. They want people to understand that caring is both rewarding and challenging. Carers want their role to be valued, but do not want to be seen as saints or victims. By increasing awareness and understanding in the broader community it is hoped that carers will report greater recognition and that society values their caring role. We also hope that awareness raising activities will encourage hidden carers to seek support.

There are four Strategy projects in this focus area:

- 3.1 Media campaigns to raise the profile of carers
- 3.2 Embed and improve information for carers
- 3.3 Young carer mobile application (app)
- 3.4 Information for carers in Aboriginal communities.

As significant progress has been made in this focus area, this report will highlight achievements in all four projects. Together these ongoing projects are improving carers' access to quality information and improving broader community understanding of carers.

Highlight Project 3.1 Media campaigns to raise the profile of carers

Lead agency

The Department of Family and Community Services (FACS)

Identified need

Greater community awareness of carers is important because it directly relates to the attitudes carers encounter every day. Greater awareness helps people to identify as a carer and helps carers to seek the information and support they need.

Project description

The project aimed to develop an ongoing media campaign to raise community awareness of carers.


Progress to date

The project established a working group with Carers NSW and other partners including NSW Health, NSW Carers Advisory Council, Multicultural NSW, an Aboriginal Carers Strategy working party member and FACS Media and Communications.

The project developed a media campaign called *Care for a Carer* with a professionally designed website as its platform. The website includes:

- A one minute video featuring real carers with diverse caring responsibilities and highlighting the need to care for carers
- Carer stories
- Practical suggestions about how to support a carer.

Care for a Carer was launched in Carers Week 2014.



14,607
total visits to the '*Care for a Carer*' website
since its launch

During Carers Week 2015, the media campaign was promoted in mainstream media publications to improve visibility resulting in increased website views from 327 in September 2015 to over 2,700 in October 2015.

Key achievements

- 2014: Development of a media campaign *Care for a Carer* including video and website (www.careforacarers.nsw.gov.au).
- 2015: Development of print advertisements for the Daily Telegraph and Sunday Telegraph, online advertisements and social media to enhance the general public's understanding of carers and link them to the *Care for a Carer* website to access more information.
- 2016: *Care for a Carer* website enhancements, including a contemporary new design and new content. New information was included to encourage more people to visit the website so that they can learn more about carers and how to support them.
- The *Care for a Carer* website has been visited more than 14,600 times since it was launched in Carers Week 2014⁴.

Next steps

As this project is ongoing, FACS is reviewing the campaign and seeking feedback to improve future campaigns, focusing on increasing the number of website visits and shares of the video through social media.



1 in 10 people are carers in NSW

"I'm proud to know that because of me, Mum enjoys her life and is still part of the community"
- Greg, full time carer for his mum Lyn.

Greg is the full time carer for his mum Lyn, whose degenerative spinal condition limits her mobility and causes pain. He helps her with medications and pain management, he supports her to use walking aides and takes her wherever she needs or wants to go.

Carers may not ask for your help or support - but that is not because they do not need it. Carers might not tell you that they miss going out with you - but they probably do. It might surprise you to know how easy it is to **care for a carer.**

NSW
MAKING IT HAPPEN

Find out how at
www.careforacarers.nsw.gov.au

⁴ Google analytics for *Care for a Carer* www.careforacarers.nsw.gov.au

Highlight Project 3.2 Embed and improve information for carers

Lead agency

Healthdirect Australia and Carers NSW with the Department of Family and Community Services (FACS)

Identified need

Carers have said that access to accurate and trusted information can help them in their caring role. Carers report that the wealth and depth of information available via websites is often difficult to understand and time consuming for carers to find relevant information, as well as know what is reliable and accurate.

Project description

This project aimed to improve the quality and accuracy of information to help carers to access information in the trusted systems they frequently use.

Progress to date

The project established a working group including lead agencies and NSW Ministry of Health, Aboriginal Disability Network NSW, Association of the Relatives and Friends of the Mentally Ill (ARAFMI) NSW, Council on the Ageing NSW, Motor Neurone Disease Association of NSW and Carer Assist.

Information on the Healthdirect Australia website *Caring for Others* page was reviewed and revised (www.healthdirect.gov.au) so that it could be more easily found through searching the internet.

The review process ensured information included instructions to prompt the user to click through to get more information and was relevant to the topics that carers usually search for on the internet, such as their health needs. Consumer research with approximately 1,000 people informed the initial re-development of the website content.

The project developed a search widget which enables access to Healthdirect Australia's National Health Services Directory which includes carer supports and services. The widget was developed for use by Carers NSW staff who support a telephone helpline. The widget increases the number of services they can access when searching for services for carers.

This project helped to enhance the quality of information for carers as well as targeting organisations to become Healthdirect Australia information partners.

Key achievements

Baseline data is being collected for evaluation in the future, for example:

- The Healthdirect Australia website *Caring for Others* page has received 29,900 total visits (since 24 July 2015). 80 per cent of these visits have come from Google searches.
- The revised content has led to improved traffic to all carer pages on www.healthdirect.gov.au.
- Healthdirect Australia manages Carer Gateway on behalf of the Department of Social Services. Carer Gateway is a national phone and online service (www.carergateway.gov.au) that was launched on 14 December 2015. Carer Gateway provides practical information and resources to support carers, connecting carers to local support services. The background research completed for this project informed aspects of the development of Carer Gateway.

Next steps

Content will be reviewed every two years to:

- Ensure existing content on www.healthdirect.gov.au addresses the needs of carers
- Enhance landing pages to align with the scope of the NSW Carers Strategy
- Ensure relevant content is displaying in internet search results
- Encourage other organisations to link to Healthdirect Australia carer content
- Ensure relevant information is being promoted.

In the future there is potential to explore how to reach carer target populations with a greater presence on Facebook, for example, women aged 39-50 years.

The screenshot displays the Healthdirect Australia website interface. At the top, a navigation bar lists categories: General health, Pregnancy and parenting, Mental health, Aged care, and Caring for someone. The main header includes the Healthdirect logo and the tagline 'Free Australian health advice you can count on.' Below the header, a search bar and navigation links (Home, Health topics A-Z, Medicines, Symptom checker, Service finder) are visible. The central content area features a large image of two hands holding each other, with the heading 'Caring for others' below it. The text under this heading discusses the role of carers and introduces Carer Gateway. A sidebar on the right contains 'Related Pages' with links to various health conditions and a 'Symptom Checker' section.

Highlight Project 3.3 Young Carer App - *Who Cares?* A mobile app for young carers

Lead agency

The Department of Family and Community Services (FACS) with Carers NSW

Identified need

There are more than 105,000 young carers in NSW. Research highlights that many young carers experience social stigma, isolation, anxiety and fatigue because of their caring role. There is also evidence that overall young carers are less likely to complete high school or be employed than their peers. Many young carers do not identify as a carer and therefore do not access available supports.

Research by the Australian Communications and Media Authority (ACMA) indicates that approximately 72 per cent of all Australian young people (aged 14-24 years) are accessing the internet more than three times a day using their mobile phones⁵. Young carers involved in developing the Strategy suggested that a mobile app would be an effective way to reach young people who have caring responsibilities and provide them with information.

Project description

The project aimed to develop a mobile app with and for young people with caring responsibilities, to encourage them to self identify as carers and get the support they need.

Progress to date

The app was developed through the NSW Finance and Services' *Apps4NSW* competition. It was co-designed by young carers from across NSW and app developers who entered the competition.

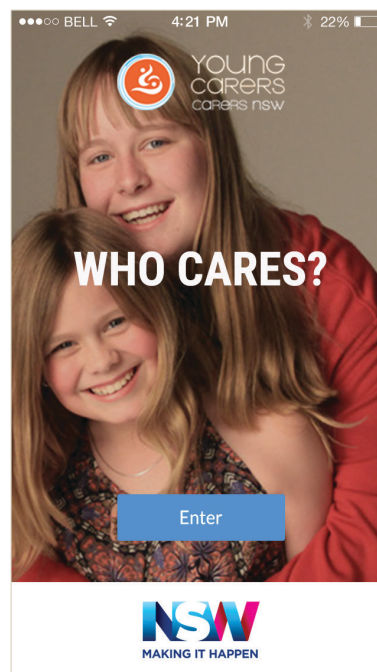
The young carers who helped to design the app developed their technical skills, as well as their individual confidence and team work skills. Young carers appeared in the *Apps4NSW* pitching video to encourage and educate developers entering the competition and were also involved on the judging panel for the competition.

Who Cares? was launched by the Hon. John Ajaka MLC, NSW Minister for Disability Services and Minister for Ageing in October 2015.

⁵ Australian Communications and Media Authority, Aussie kids and teens online, February 2016, www.acma.gov.au/theACMA/engage-blogs/engage-blogs/Research-snapshots/Aussie-teens-and-kids-online

Key achievements

- Developed *Who Cares?*, a free mobile app available to download through iTunes App Store and Google Play.
- *Who Cares?* has been downloaded more than 200 times and its content viewed online more than 1,350 times to date. Both trends have been steadily increasing since launch.



Next steps

- *Who Cares?* has been promoted on websites such as the national Carer Gateway, Carers NSW, FACS, Youth NSW and Healthdirect Australia. The Carers NSW Young Carer Team promote *Who Cares?* through competitions and when presenting to their young carer network.
- The success of the app is now about working with young carers to improve content and better target communications and promotion to increase reach and the number of young people accessing and sharing it.
- Exploring new partnership work, such as recent collaboration with the digital marketing team at Johnson & Johnson Family of Companies in Australia.

Highlight Project 3.4 Information for carers in Aboriginal communities

Lead agency

The Department of Family and Community Services (FACS) with the Aboriginal Carers Strategy working party established to provide advice on the project

Part 1: *Taking care of business – planning ahead for Aboriginal people in NSW*

Identified need

Aboriginal carers have said that they worry about planning ahead for their family's future, sharing stories about the trauma and family conflict they have experienced when someone in their family dies without a Will. Anecdotally Aboriginal people have a low rate of Will-making. They want useful and culturally appropriate information to help them with future planning.

Aboriginal carers also told us that they need information provided to them multiple times and in different formats to suit different people. Ongoing promotion of the resource in different ways is critical to ensuring the information reaches Aboriginal carers.

NSW Trustee & Guardian has developed strong and positive relationships with other organisations such as The Benevolent Society, Carers NSW, NSW Fair Trading, Good Services Mob (a coalition of government agencies that do outreach into Aboriginal communities), Public Guardian and key Aboriginal service providers

NSW Trustee & Guardian

Project description

The project aimed to update an existing planning ahead resource targeted to Aboriginal people (*Taking care of business*), and ensure it is culturally appropriate as well as expand the information to all parts of planning ahead to include Powers of Attorney and Enduring Guardianship.

Progress to date

The project established the Aboriginal Carers Strategy working party to provide advice on the project. The working party comprises people who are leaders in their field and strongly connected to their communities and includes: the Aboriginal Disability Network NSW, Gathering Committee, Yarkuwa Indigenous Knowledge Centre, Aboriginal Affairs, National Disability Services, NSW Health (Primary Health Network), Link-Up NSW, NSW Carers Advisory Council, Carers NSW, NSW Trustee & Guardian, NSW Public Guardian and The Benevolent Society.

Using links to Aboriginal communities provided by the Aboriginal Carers Strategy working party, NSW Trustee & Guardian and Public Guardian held consultation sessions with Aboriginal carers and other key stakeholders to get feedback on *Taking care of business*. Consultation groups were held with Aboriginal elders, community members and service providers in Campbelltown, Moree, Coonabarabran, Dubbo and Albury Wodonga. The groups were asked what they thought of the resource and how they would like to receive this kind of information and their feedback was considered in the development of the final publication.

Taking care of business is written in easy to understand English and uses case studies and illustrations to communicate key messages in a culturally appropriate way. It has been delivered through effective, face-to-face engagement with the Aboriginal community and key service providers.

NSW Trustee & Guardian aligned the distribution and promotion of *Taking care of business* with the *Aboriginal Wills Handbook*. The Handbook targets the legal practitioner on culturally appropriate Wills for Aboriginal people. Aligning the two publications has been positively received by legal practitioners.

“I really like the stories and tips, they sound Aboriginal”

“This is really good this info, important”

“Well you’ve convinced me love! (regarding the importance of having planning ahead documents in place)”

Community feedback on *Taking care of business* 2015

The two resources have been distributed and promoted through service providers, NSW Trustee & Guardian’s website and community education sessions delivered by Public Guardian and NSW Trustee & Guardian.

Members of the Aboriginal Carers Strategy working party have promoted the resources through their education and information sessions.

The Aboriginal Carers Strategy working party also provides cultural advice on a number of other Carers Strategy projects.

Key achievements

- The updated version of *Taking care of business* was publicly released in June 2015 and is available on the NSW Trustee & Guardian website www.tag.nsw.gov.au.
- 15,000 printed copies have been distributed to government and non-government organisations and Aboriginal communities.
- Information about *Taking care of business* has been circulated to 65,000 clients and key stakeholders via the NSW Trustee & Guardian newsletter.
- Inclusion of *Taking care of business* into 4,000 of The Benevolent Society’s client information packages for Aboriginal people across NSW.

- Community education sessions delivered in NSW metropolitan and regional centres to thousands of community elders and key service providers about planning ahead, for example, NAIDOC event National Centre for Indigenous Excellence in Redfern, Aboriginal Carers Women's Retreat in Collaroy, Good Services Mob presentations across many locations in NSW, *Getting Ready Together* conference in Wollongong.

The Benevolent Society and the NSW Carers Strategy have brought about many positive outcomes for Aboriginal and Torres Strait Islander clients and communities. Often unrecognised as carers, it has given the community recognition and a voice to express their needs to fulfil their caring roles.

Sharlene McKenzie
Aboriginal Senior Practitioner, The Benevolent Society

Next steps

The Aboriginal Carers Strategy working party is continually exploring different strategies to promote *Taking care of business* to community. An ongoing challenge is how to distribute and promote *Taking care of business* to more regional, rural and remote areas.



15,000

copies of '*Taking
care of business*'
distributed in NSW

Part 2: Develop a template for Aboriginal carers to share key information about the people they care for

Identified need

Sometimes an Aboriginal carer is the sole holder of key information about the people they care for. They worry about how to share this information if someone else has to suddenly step in and help because they are unavailable, for example, if they need to go to hospital or attend to Sorry Business.

Project description

The project aimed to develop an emergency care and contacts template for carers to document key contacts for those they care for and which can be shared with other family members. The template will be able to be adapted to reflect different community needs.

Progress to date

This project is in its early stages. So far the Aboriginal Carers Strategy working party has developed a draft template for carers to document key information about the person they care for in a format that they can easily share with other family members. The template is generic and therefore can be tailored by individuals or local communities with photos or local artwork and images.

Knowing that key information about the people they care for is recorded and shared with other family members brings peace of mind to Aboriginal carers. Other family members can then easily step in and help support the carer if required.

Initial feedback on the template is positive. Carers have reported that the template has initiated the process of recording and sharing information with other family members which has been very helpful.

Key achievements

- Two versions of the draft emergency care and contacts templates have been developed by two Aboriginal organisations, Link-Up NSW in Mount Druitt and Yarkuwa Indigenous Knowledge Centre in Deniliquin. The two versions reflect local needs and they have been piloted with Aboriginal carers in their local areas.

Next steps

The next stage of the project will be to further develop and test the template and then distribute and promote it in Aboriginal communities.

Focus area 4: Carer engagement

Expected outcome in the Strategy

Carers are involved in decisions that affect them and the people they care for

Summary of progress

Carers told us that they wanted to be actively involved in the design and delivery of services.

There are three Strategy projects in this focus area:

- 4.1 Partners in care – health care
- 4.2 Partners in care – community service delivery
- 4.3 Engaging carers in local decision making.

The projects aim to improve the ways we involve carers as partners in the care delivered for their loved ones and also increase their involvement in local decisions about the design and delivery of services.

Project 4.2 Partners in care (community service delivery)

Part 1: Providing training and information about carers to Housing NSW Staff

Lead agency

Carers NSW

Identified need

Many carers in social housing do not identify as carers; that is, they may be 'hidden carers' who do not access the services and supports available to them.

Project description

The project aimed to help people living in social housing with caring responsibilities, and who do not identify as a carer, to access services and supports.

Progress to date

Carers NSW and the Department of Family and Community Services (FACS) developed a multi-pronged approach to support carers in social housing to access services and supports:

- Supported Housing NSW staff to better engage and support carers through training and providing quality information about carers.
- Reached out to hidden carers living in social housing (including public housing and community housing) and provided them with support through outreach and carer specific activities.
- Developed an eLearning tool for social housing staff, to increase their awareness about hidden carers: why they are hidden, how to identify them and how to connect them with services and supports.
- Developed a suite of flyers for social housing staff, suitable for distribution to different groups of carers, about the services and supports available to them.

A large number of partners from metropolitan and regional locations were involved in the implementation of this project, including Aboriginal, social housing, Government and community organisations, such as the National Centre of Indigenous Excellence, Northern Links NSW Inc, Samaritans Foundation, Bidwill Uniting, The Junction Works Ltd, Illawarra Aboriginal Corporation and Intereach NSW Inc.

All hidden carer events were held in partnership with other service providers, Tenant Participation Resource Service providers, Community Housing Program providers and Aboriginal organisations.

Key achievements

- Twelve hidden carer events were held in social housing areas across NSW. Approximately 6,700 people attended the events. Carers NSW staff spoke with 1,185 people, provided them with brochures and explained what services are available.
- Support in the form of information and referral was provided to 535 people.
- ELearning module developed and available to social housing staff (FACS and other providers).
- Flyers designed, printed and delivered to 77 FACS housing offices.
- Partner organisations have increased their understanding of who carers are, how to identify hidden carers, and the supports and services that are available to them.

Next steps

FACS provided one-off funding to deliver the project, and will continue to support carers in public housing to be identified and informed.

6,700

attendees at hidden
carer events held in
social housing areas
in NSW

Part 2: *Providing training to carers about the National Disability Insurance Scheme (NDIS)*

Lead agency

Carers NSW

Identified need

With the transition to the National Disability Insurance Scheme (NDIS) underway, carers require relevant and timely information so that they, and the person they provide care for, can access the services and supports available to them.

Project description

The project aimed to provide information about the NDIS to carers and their families.

Progress to date

Carers NSW developed a half-day workshop *Carers and the NDIS* for carers of people with disability. The workshop provided carers with a general introduction to the NDIS, information about how to support the person they care for to access the NDIS, and how to prepare themselves to communicate their own needs in relation to the NDIS.

Key achievements

- The workshop was delivered from November 2015 – May 2016 in over 20 different metropolitan and regional locations and was well-received by carers. More than 330 people participated in the workshops.
- Questions asked by carers during the workshops are being collated and shared with the Carers NSW policy team, providing a greater understanding of carer needs to inform policy and advocacy work.

“Enjoyed the workshop ... My awareness of NDIS and my function as a carer has increased in regard to accessing the NDIS”

“Didn’t realise we carers had acknowledgement in NDIS”

“Very informative, made it easier to understand. Now on right track. Thank you.”

“We have a lot more to learn but thankful for getting started in a new difficult big change, a big learning curve.”

Feedback from *Carers and the NDIS* workshop participants

Next steps

Steps are being taken to ensure that information about the NDIS reaches carer support groups across New South Wales.

Focus area 5: Improving the evidence base

Expected outcome in the Strategy

Carers policy and practice is informed by quality evidence

Summary of progress

There is one Strategy project in this focus area:

5.1 Using the evidence base about carers

The project aims to improve the use of available evidence about carers in the development of policy and programs. For example, a new question was added to the NSW Public Sector 2016 *People Matter Employee Survey*. This, together with the forthcoming Australia Bureau of Statistics 2015 *Survey of Disability, Ageing and Carers* (SDAC) results, and other data sources including the biennial Carers NSW *Carers Survey*, will provide improved evidence.

Assessment of the effectiveness of Strategy projects to show achievement of outcomes for carers across the focus areas will also contribute to the evidence base for future carer policy and initiatives.

Future Strategy work will focus on developing a plan to draw together the evidence base and develop strategies to make the evidence more accessible to policy makers.

“Do you provide care for others outside of work?”

Are you the principal carer for someone who needs support due to disability, chronic illness, mental illness, dementia or frail age?”

Questions about caring responsibilities in the
NSW Public Sector 2016 *People Matter Employee Survey*

Governance and reporting

The Department of Family and Community Services (FACS) leads the governance of this Strategy and convenes the Carers Strategy Implementation Committee (the Implementation Committee), which was established in April 2015.

The Implementation Committee comprises representatives from: NSW Ministry of Health; Carers NSW; Department of Social Services; NSW Department of Education; NSW Trustee & Guardian; NSW Mental Health Commission; Healthdirect Australia; NSW Community Services and Health Industry Training Advisory Body; NSW Carers Advisory Council and FACS. Membership also includes two Aboriginal representatives from The Benevolent Society and the Aboriginal Disability Network NSW nominated from the Aboriginal Carers Strategy working party (*Project 3.4 Information for carers in Aboriginal communities*) to provide an Aboriginal perspective.

The role of the Implementation Committee is to oversee the implementation, monitoring and evaluation of the Strategy including specific projects and long term directions. The Implementation Committee oversees the development of individual projects and Strategy program logics where activities and inputs are clearly linked to outputs and carer outcomes.

The Implementation Committee is chaired by FACS and meets to provide direction and advice on Strategy project implementation, progress, achievements and outcomes.

Three key principles guide the implementation of the Strategy:

- Support clear alignment between the aims, process measures and outcome measures for each Strategy project so they achieve the intended outcomes for carers. This has been achieved by applying a standardised program logic framework to all Strategy projects.
- Improve consistency in data collection and reporting across projects to inform improvements.
- Plan for continuous monitoring of the Strategy, which was achieved by incorporating all the program logics into an overarching Strategy framework (Appendix A).



Next steps

This Report shows what has been achieved over the past two years, but there are still three years to go in the NSW Carers Strategy.

Carers can best be supported through partnerships with the broader community, including carers themselves. Not only have carers supported the development and implementation of projects in the Strategy, they are helping to prioritise future work.

Work will continue on collecting and analysing data to measure achievement of Strategy outcomes across the focus areas, including consolidating the data to improve its use in carer policy and programs (Focus Area Five).

The NSW *Carers (Recognition) Act 2010* will also continue to be implemented following its statutory review in 2016. The Government's commitment to both the Act and the Strategy will see continual improvements for carers in NSW.

Acknowledgements

The NSW Government would like to acknowledge and thank all our NSW Carers Strategy partners, supporters and champions. The Strategy has been a collaborative effort since its inception. We are grateful for the contributions and continued involvement of so many as we work together to improve the position of carers in NSW.

In particular, we acknowledge the carers who have been involved in implementation of the Strategy, and our key engagement partners since the beginning of the journey - the NSW Ministry of Health, Carers NSW, and the Department of Social Services.

We acknowledge and thank the members of the Carers Strategy Implementation Committee, the NSW Carers Advisory Council, the Aboriginal Carers Strategy working party and all project steering committees.

We would like to pay tribute to the carers who have so generously shared their knowledge, expertise and lived experience with us. You are the reason for the Strategy, and it is your involvement and support that make it possible.

Appendix A – NSW Carers Strategy 2014-2019 Monitoring & Evaluation Program Logic

Focus area	Inputs/Activities (2016)	Outputs (2017)
EMPLOYMENT & EDUCATION Carers Strategy projects 1.1-1.5	<ul style="list-style-type: none"> • Projects 1.1 & 1.3 deliver planned inputs on budget & on time • <i>SkillsLink2Work</i> consultation, web development, monitoring & launch • Establishing & monitoring projects 1.4 and 1.5 	<ul style="list-style-type: none"> • Quantitative & qualitative baseline data collected & analysed for 1.1 – 1.5
CARER HEALTH & WELLBEING Carers Strategy projects 2.1 & 2.3	<ul style="list-style-type: none"> • Identified health programs, services & health information targeted & promoted to carers • Identified carer peer support initiatives planned and commenced • Health service provider information networked 	<ul style="list-style-type: none"> • Baseline data for carer awareness already established for project 2.1 • Data base established & baseline data collected and analysed for project 2.3 • Baseline data for health service provider awareness of carer needs and issues already established
INFORMATION & COMMUNITY AWARENESS Carers Strategy projects 3.1-3.4	<ul style="list-style-type: none"> • Media campaign development & launch; campaign website update • Development & distribution of Taking Care of Business. Emergency care contacts template piloted • Establishing & monitoring the use of video & web resources 3.1-3.3 	<ul style="list-style-type: none"> • Quantitative & qualitative baseline data collected & analysed for 3.1 – 3.4
CARER & STAKEHOLDER ENGAGEMENT Carers Strategy projects 4.1- 4.3	<ul style="list-style-type: none"> • On-line projects live & promoted • All frameworks & print resources developed and distributed, events & workshops delivered • Initiatives to improve access to training & support for carer representatives OR framework & resources on carer engagement • Feasibility analysis for identification of carers in the NSW Health Patient Administration systems 	<ul style="list-style-type: none"> • Quantitative & qualitative baseline data collected & analysed for 4.1 – 4.3 for carer & stakeholder engagement activities
EVIDENCE BASE Carers Strategy project 5.1	<ul style="list-style-type: none"> • Identify project owner, key stakeholders & commit resources 	<ul style="list-style-type: none"> • Scan, review and meta-analysis of national, international and grey literature

Short term outcomes (2018)	Intermediate outcomes (2019)	Long term outcomes (2019+)
<ul style="list-style-type: none"> • More carers & employers are networked & use existing workplace flexibility • Carers & other stakeholders are using & promoting <i>SkillsLink2Work</i> • More schools, DEC welfare units & mentoring providers have the knowledge & skills to identify & support young carers 	<ul style="list-style-type: none"> • Increase the use of existing workplace flexibility by carers & their employers • More carers recognise the skills & expertise they bring to employment & training • More young carers receive support at school to transition to further education & training 	<ul style="list-style-type: none"> • Carers have choices & opportunities to participate in paid work • Young carers complete school & transition to further education & employment
<ul style="list-style-type: none"> • Increased awareness by carers of health services & programs • Carers are more aware of available local & state-wide networks • Increased awareness by health service providers of carers needs & issues 	<ul style="list-style-type: none"> • Improve the design and delivery of services and programs to make it easier for carers to look after their own health & wellbeing 	<ul style="list-style-type: none"> • Carers experience good health & wellbeing
<ul style="list-style-type: none"> • More young people and young carers, are aware of & use the App • Raised awareness of <i>Taking care of business</i> resource & the emergency care contact template • Increased community awareness & understanding towards carers 	<ul style="list-style-type: none"> • Young carers App & carer website are frequently used & improves the quality of delivered information • Aboriginal carers access & use culturally appropriate information • Increase the number of people with an understanding of carers lives 	<ul style="list-style-type: none"> • Carers are able to easily access information when they need it • Aboriginal people including carers have access to culturally appropriate resources to help them plan ahead and care. • Carers feel the broader community understands their experience
<ul style="list-style-type: none"> • Carers & stakeholders have more understanding of existing carer engagement patterns & resources • Carers access <i>Getting ready for the NDIS</i> module • Increased service provider awareness of the value of involving with & consulting carers • Identified public sector agencies & Ability Links providers have improved access to training & are more aware of carer engagement 	<ul style="list-style-type: none"> • More carer awareness of engagement opportunities, including with key program providers & NDIS support • More 'hidden' carers & carers in social housing are linked to & access support & services • Stakeholders build capacity to engage more with carers, & increase their awareness of carers needs, supports & services 	<ul style="list-style-type: none"> • Increase in trained and supported carer involvement in policy & in decision making that affects them, & in the design & delivery of identified services • Positive behavioural change towards carers from stakeholders, & NDIS plans & budgets include awareness of carer needs
<ul style="list-style-type: none"> • Evidence gaps are identified, research agenda implemented 	<ul style="list-style-type: none"> • Publish a fully referenced & annotated literature search 	<ul style="list-style-type: none"> • Carers policy & practice is informed by quality evidence & better use made of available data

Appendix B – Update on NSW Carer Strategy Projects

The NSW Carers Strategy includes 16 projects in total and can be found here www.facs.nsw.gov.au/reforms/carers/nsw_carers_strategy.

Project 1.1 Network of employers to champion carer friendly workplaces -

develop a network of progressive employers to champion better employment outcomes for carers.

Status: In progress.

- A successful forum was held with employers interested in joining a network to champion carer-friendly workplaces. A market scoping and feasibility study was completed in June 2016. Stage two will progress the most suitable model.

Project 1.2 Recognising carers' skills – develop a tool to assist carers to understand how the skills, knowledge and experience they have built up as carers, can be used in training and employment.

Status: Completed. See highlight report on page 11.

Project 1.3 Carers working in the NSW Government sector - explore opportunities to incorporate a carer focus into existing public sector guidelines, policies and surveys and ongoing implementation of the *NSW Carers (Recognition) Act 2010*.

Status: In progress.

- In 2016 the NSW Public Service Commission's *People Matter Employee Survey* incorporated a new carer demographic question. This will provide the baseline data about the number of carers working in the public sector.
- FACS Strategic Human Resources has developed an action plan to promote carers in existing HR and workforce management policies and programs including flexible working arrangements, equity and diversity policies, and induction and leadership programs.
- Together with Converge International, a leader in workplace mental health and provider of the FACS Employee Assistance Program, FACS will create and share content to raise awareness of the workplace challenges faced by carers.
- Review of the *Carers (Recognition) Act 2010* will inform a renewed push to support implementation of the Act.

Project 1.4 Support for carers at schools – build the capacity of schools to identify and respond to the wellbeing of young carers.

Status: In progress.

- In 2014 the Department of Education updated its student wellbeing webpage with information about young carers. The next stages of the project will involve a review and update of this information and also their internal resource, *Being a Carer, Being a Student, Being a Kid*.
- In 2016 information regarding young carer initiatives has been distributed to Department of Education Operational Directorates. This included *Who Cares?* a mobile app for young carers and the #YCProject Short Film to help raise awareness about young carers. FACS and the Department of Education will continue to support initiatives that help schools at an operational level to identify and support young carers at school.

Project 1.5 Young carer mentoring - work with young carers, government agencies and non-government service providers to increase young carers access to mentoring programs.

Status: Stage 1 Completed and ongoing.

- A young carer mentoring roundtable was held in November 2014 with mentoring providers, young carers and government agencies. The roundtable provided an opportunity to learn and discuss young carers' current access to mentoring and to explore options for a young carer mentoring initiative in NSW.
- A report from the roundtable with recommendations and options for a young carer mentoring or support initiative will inform the next stage of the project.

Project 2.1 Easier access to health care - develop strategies to make it easier for carers to access health services and programs.

Status: In progress. See highlight report on page 14.

Project 2.2 Individualising respite and support services – provide a watching brief for carers on the key reforms such as the NDIS.

Status: Ongoing.

- FACS is providing clear messages about carers in the rollout of major reforms such as the NDIS.

Project 2.3 Carer peer support - expand the variety and reach of peer support programs for carers in NSW.

Status: To be commenced in 2017.

- The Carers NSW carer support group database holds information about 266 carer support groups across NSW. The database is searchable by area and available on the Carers NSW website.
- A working group will be established with key stakeholders including the NSW Mental Health Commission.
- The next stage of this project will involve reviewing the database and identifying any potential improvements; and then developing a broader plan to improve information about carer peer support opportunities.

Project 3.1 Media campaigns to raise the profile of carers - develop ongoing media campaigns to improve public awareness and understanding of carers and their lives.

Status: Completed and ongoing. See highlight report on page 18.

Project 3.2 Embed and improve information useful for carers – improve the quality and accuracy of information for carers in systems they frequently use.

Status: Completed and Ongoing. See highlight report on page 20.

Project 3.3 Young carer mobile application (app) – develop a mobile app to help young people with caring responsibilities to self-identify and connect to available support.

Status: Completed and ongoing. See highlight report on page 22.

Project 3.4 Information for carers in Aboriginal communities – provide culturally appropriate information about services, supports and how to plan ahead.

Status: Completed and ongoing. See highlight report on page 24.

Project 4.1 Partners in care (health care) - support carer engagement and input in the health system through developing care planning tools and an e-learning module.

Status: In progress.

- *Partnering with Carers* module developed for NSW Health staff across nursing, medical, allied health and management staff as well as corporate services, hospital and technical support staff.

Project 4.2 Partners in care (community service delivery) – support carers to make the most of new opportunities offered by the NDIS and person-centred approaches.

Status: Completed. See highlight report on page 28.

Project 4.3 Engaging carers in local decision making - make it easier for government and other public sector agencies in NSW to engage carers in decision making about policies and programs that impact on them.

Status: In progress.

- Partner organisations from across NSW attended a roundtable where they committed to work collaboratively in providing carer representation programs and services.
- Focus groups with carers and feedback/information gathered through the NSW *Carers (Recognition) Act 2010* review will be used to inform the next stages of the project.

Project 5.1 Improving the evidence base - consolidate evidence on Strategy focus areas and carers and identify ways it can inform policy and practice.

Status: In progress.

- The Implementation Committee has worked with Strategy project leaders to develop the NSW Carers Strategy 2014-2019 Monitoring & Evaluation Program Logic (at **Appendix A**).
- The Program Logic will provide a framework for collecting and analysing data to measure the success of the Strategy against short, intermediate and long-term outcomes for carers.
- Work will begin to consolidate the evidence about carers and identify ways it can inform policy and practice.

