



Family &
Community Services

NSW Carers Strategy Summit Background Paper



1 Introduction

About one in ten (850,000) people in NSW provide ongoing unpaid support to family or friends who need help with everyday aspects of life because of:

- disability;
- chronic illness;
- mental illness; or
- frail age.

Carers come from all walks of life, cultural backgrounds and age groups. Each caring situation is unique, and each carer has individual needs. Carers can be family members, friends, housemates or neighbours. Both men and women can become carers although women are more likely to take on the primary caring role.

Many of us will find ourselves either caring for someone or being cared for at some stage in our life.

1.1 The NSW Carers Strategy

The NSW Carers Strategy is intended to set the NSW Government's policy direction to improve the lives of carers in NSW. The Strategy will create a shared agenda to be implemented across government in partnership with the community, private sector and non-government organisations. It is hoped that the Strategy will make practical differences to carers.

The Strategy complements the *NSW Carers (Recognition) Act 2010* by supporting government and non-government organisations to go beyond the minimum requirements contained in legislation.

1.2 NSW Ministerial Carers Strategy Summit

The NSW Ministerial Carers Strategy Summit is the final stage of the collaborative process used to develop the NSW Carers Strategy.

The Summit has the following broad objectives:

1. Bring together the best ideas from each of seven focus areas that were covered in the collaborative process.

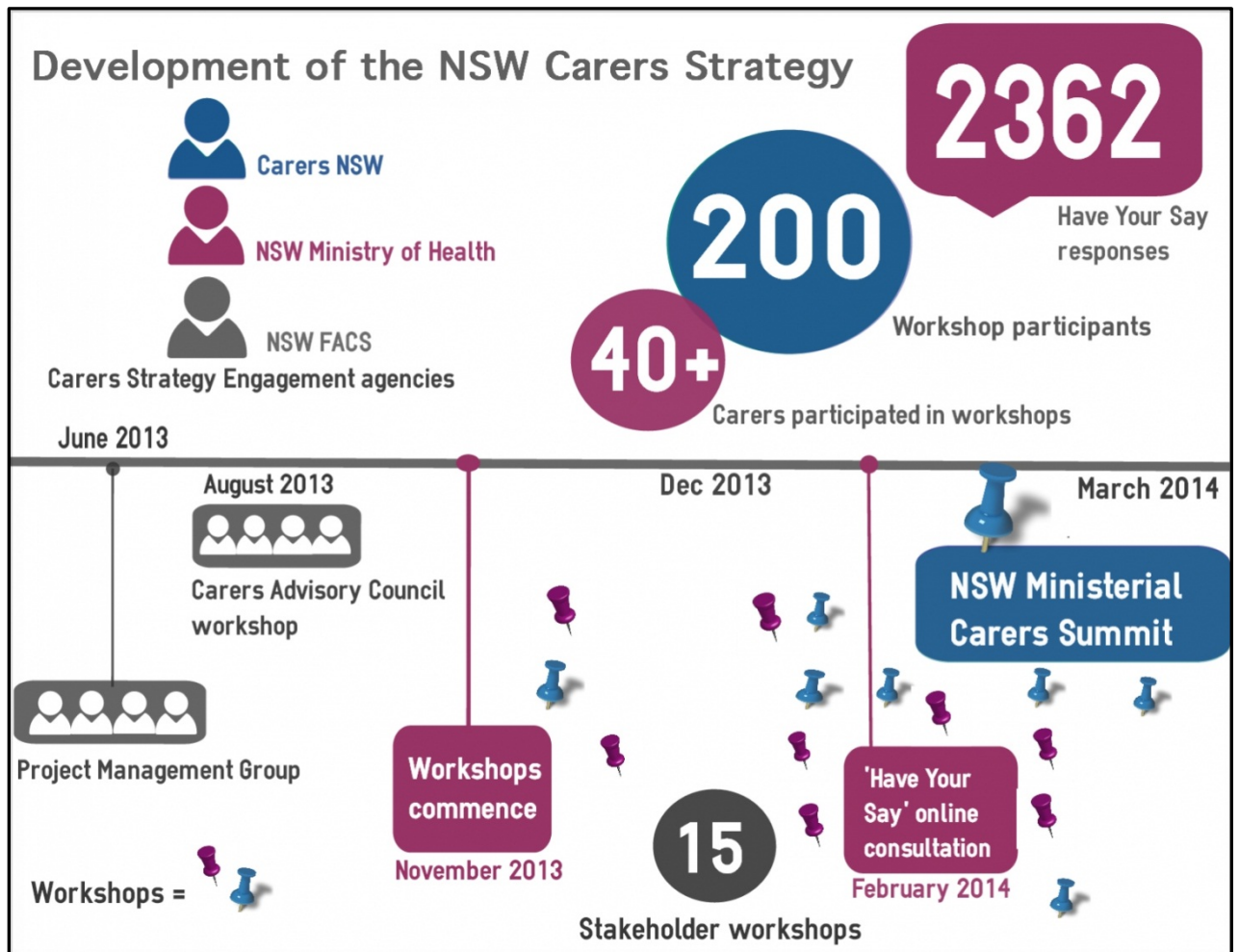
The focus areas are:

- employment;
- health and wellbeing;
- young carers;
- information and community awareness;
- carer engagement;
- improving the evidence base; and
- caring in Aboriginal communities.

2. To provide advice from stakeholders on the best solutions for carers in NSW that should be included in the NSW Carers Strategy.

2 Overview of the Process

2.1 The journey – how we got here



2.2 The process so far

Collaboration with stakeholders

The Strategy has been developed using a collaborative co-design approach. This involved bringing together carers and all our other stakeholders with the aim of achieving a shared understanding of the issues and developing the most effective and enduring solutions.

This approach was chosen because the NSW Government cannot do this work alone.

Involving carers at each step of the process has resulted in better ideas that are informed by carers' own lives. Collaborating with employers, government, non-government, industry representatives, experts and researchers has brought new ideas, different thinking and created opportunities for new partnerships to improve the lives of carers in practical ways.

This approach was always expected to generate more potential solutions than it was possible to include in the final Strategy. By identifying the full range of possible initiatives, it was hoped that those projects that could have greatest impact and could be supported by the necessary partners would emerge.

Co-design Workshops

Between November 2013 and March 2014, 15 workshops with approximately 200 participants took place to develop practical solutions across the following focus areas:

- employment;
- health and wellbeing;
- young carers;
- information and community awareness;
- carer engagement;
- improving the evidence base; and
- caring in Aboriginal communities.

Each workshop included carers, non-government organisations, private sector organisations, public servants from all levels of government, frontline workers (eg nurses and school principals) and academics. A full list of workshops and dates can be found at Appendix A.

Most workshops followed a two stage process:

1. The first workshop considered and explored what was working well for carers, what should be improved and what success would look like. Workshop participants developed a 'long list' of ideas and solutions that were within the areas of State Government responsibility or influence. Participants were encouraged to test out their ideas and solutions with colleagues, friends and family.
2. The second workshop refined the 'long list' of solutions and evaluated each project based on its impact and whether it was able to be achieved through a NSW Government led strategy. Each group agreed a short list of the more useful projects that deserved further work.

Specific workshops were held with Aboriginal communities in Dubbo, Redfern and Mount Druitt that involved broader discussions about caring in Aboriginal communities the needs of Aboriginal carers.

The collaboration included carers and other stakeholders from culturally and linguistically diverse communities (CALD) and those from rural and remote regions. The Government supported participation of carers through reimbursement of expenses and engaged CALD carers and agencies to contribute to the process.

'Have Your Say' online consultation

An online survey was conducted using the NSW Government's Have Your Say website from 10 February – 7 March 2014. We received 2362 responses to the survey.

The survey asked respondents to vote on the 'short list' of the best solutions from each of the workshops and provide comment as to how they should be implemented.

Governance

The NSW Carers Strategy Project Management Group was established in June 2013 to oversee the development of the Strategy. Members of the Project Management Group include representatives of State and Commonwealth Government agencies, peak bodies, private sector representatives, academics and members of the NSW Carers Advisory Council.

The Minister's Carers Advisory Council has also played a key role in the development of the Carers Strategy. Members have participated in workshops and provided input at key stages.

From the Workshops to the Summit

In preparing for this Summit, the Office for Carers has met with stakeholders to further develop the ideas and solutions from the workshops and to create the partnerships and resources that are needed to implement them.

Many solutions have continued to evolve as part of this process as it becomes clearer how they might work and the specific problems that each should focus on.

A number of these projects would benefit from more discussion with stakeholders, particularly with respect to how they should be implemented and what contribution different stakeholders can make to the partnerships that are needed to bring them to fruition.

The Project Management Group and the Carers Advisory Council have also worked on a collective vision for the Strategy.

This paper contains:

- the proposed collective vision (Chapter 3 - Vision);
- a summary of the short list of projects for each focus area, the other projects that were considered to have merit and feedback from *Have Your Say*. (Chapter 4 – Focus Areas);
- more detailed summaries of the solutions that are emerging as priorities (Chapter 5 – Emerging Solutions).

A simple map of the emerging solutions for each focus area is included at Appendix B. The projects in **bold** are those that would benefit from more discussion at the Summit.

WORKSHOP IDEAS → SHORT LIST → EMERGING SOLUTIONS ↔ **EMERGING SOLUTIONS FOR THE SUMMIT**

Next Steps

Following the Summit, the Office for Carers will work on developing the draft Strategy document for consideration by the NSW Government.

An implementation plan and an evaluation and monitoring framework will also be developed to guide our work over the next five years.

We expect to release the NSW Carers Strategy in mid 2014.

3 Collective Vision

The Project Management Group and the Carers Advisory Council have developed a draft vision for the NSW Carers Strategy:

We acknowledge the importance of carers in NSW and that they should be respected and valued, with the same rights, choices and opportunities as others and, importantly, the time and energy to care for themselves. To achieve this vision we have solutions that will empower carers in these areas.

This vision is a collective vision for the stakeholders that have been involved in the development of the NSW Carers Strategy.

It picks up on many of the important themes that have run through the process to date including:

- respecting and valuing carers for their contribution and their knowledge;
- the diversity of carers;
- carers want to have greater choice and control in their lives;
- carers' time, energy and resources are limited and precious to them;
- recognition and inclusion of carers; and
- the wellbeing of carers is interconnected with the wellbeing of the person(s) they care for.

4 Focus Areas

4.1 EMPLOYMENT

Proposed Outcome

Carers have choices and opportunities to participate in paid work.

The process to date suggests that the focus for reform should be on better use of workplace flexibility so that carers are better able to balance caring and work.

If successful, strategies would encourage more carers to join the workforce and improve discussions between carers and their managers. This will also deliver productivity gains for employers and prepare workplaces for expected increases in the number of working carers, particularly due to population ageing.

The short list of projects that were evaluated by the workshops as being achievable and likely to make an impact are:

- **Employers for Carers** - an employer led network to champion better employment outcomes for carers.
- **Employer resources** such as HR tools and best practice guides.
- **Recognition of Prior Learning (RPL)** a tool that helps carers get recognition for the skills they use everyday when getting a job or a qualification.
- **Flexible care options for working carers** such as respite at hours that line up with carer's work shifts, on site care and vacation care.
- **Return to work strategy** targeting people who were no longer carers and assisting them to get back into the workforce.
- **Public Sector Carers** including questions in workforce surveys and incorporate carers in workforce diversity and sector reform strategies.

Other projects that were considered to have merit are:

- Carer passport –evidence of caring responsibilities (for employers) and employment conditions (for service providers).
- Workplace audits/surveys – an audit/survey tool to support employer's implementing and monitoring carer friendly work practices.
- Further flexible training options for carers – promoted through employment agencies
- Including carers in the syllabus of business courses.
- Employer Award – awarded to progressive employers with carer friendly workplaces.

HAVE YOUR SAY

47% said that *flexibility in the provision of support services* to enable carers to combine work and care is the most important way to support carers in employment. The *Employers for Carers network* was the second most important priority, chosen by 24% of respondents.

Almost 500 respondents left comments about employment which broadly support the direction of the workshops. Comments confirmed that carers want employers and work colleagues to understand their caring role and want workplace flexibility to help them to juggle caring and employment. Carers were also clear that they wanted career choices – not just jobs.

4.2 CARER HEALTH AND WELLBEING

Proposed Outcome

Carers experience good health and wellbeing

The process to date suggests that the focus for reform should be on designing services and supports used by carers in ways that use their time, energy and resources as efficiently as possible.

Well designed services and supports are easier for carers, meaning carers are more likely to look after their own health and wellbeing. This applies to formal services, community activities and commercial businesses that carers interact with. Flexibility in formal services, particularly respite, is highly valued by carers.

The short list of projects that were evaluated by the workshops as being achievable and likely to make an impact are:

- **GP initiatives** including a Medicare billing item for carers 'carers consultation'.
- **integrated health care models** that opportunistically offer health services to carers where possible.
- **individualised and flexible respite** that give families choice and control over how resources are used.
- **carer counselling and mental health programs.**
- **introduction of a Carers' carers' card** that provides discounted products and priority access to services.

Other projects that were considered to have merit are:

- Carer friendly public spaces and venues.
- 'Carers Welcome Here' logo/sticker.
- Physical activity/exercise initiatives for carers and the person they care for based on choice.
- Healthy living awareness raising.
- Local pharmacies health screening initiative.
- Health insurance for carers.
- Professional development and training for GPs and emergency services staff about working with carers.
- Carer support groups and peer support (various models).

HAVE YOUR SAY

40% of respondents said that *improving carer access to healthy living and recreational programs (eg flexible and inclusive respite options for carers)* is the most important idea for improving carer health and wellbeing. The second most important idea, chosen by 33% of respondents, is *personal supports for carers*, for example peer support groups and carer specific counselling and mental wellbeing programs are important.

353 respondents also left comments that broadly support the direction of the workshop. One of the most repeated comments referred to the cost associated with maintaining health and wellbeing, which carers will sacrifice if financially stressed, in order to prioritise the needs of the person they care for.

4.3 YOUNG CARERS

Proposed Outcome

Young carers complete school and transition successfully to further education and/or employment

The process to date suggests that the focus for reform should be on the transition young carers who are in school or other forms of education make to independence.

If successful, young carers will feel supported to disclose that they are carers and confident that the system will assist them to achieve at school and into further training or employment.

The 'short list' of projects that were evaluated by the workshops as being achievable and likely to make impact were identified as:

- **A 'Young Carer Passport' or identification card** that would reduce the need for young carers to retell their story and provide evidence of their needs in the education system.
- **Mentoring initiatives** with a specific focus on transitioning to independence.
- **A young carer app and information portal** designed by young carers, to reach and connect more young carers to information and available supports.

Other projects that were considered to have merit are:

- School-based awareness campaign including a network of peer educators in schools.
- Increase TV/media coverage of young carer stories.
- Training and professional development initiatives that build the skills and knowledge of those working with young carers about how best to support them.
- Young carer curriculum content in teacher training.
- Young Driver/mentoring scheme with corporate sector partnership.
- Australian Tertiary Admissions Rank (ATAR) University points and/or Recognition of Prior Learning for caring.
- Academic Integration Plans for young carers (University).
- Peer based support for young carers.
- Practical supports for young carers.
- Young carer awareness campaign using social media.

HAVE YOUR SAY

49% of respondents think an *education system that enables young carers to identify and supports them* was the most important initiative for supporting young carers in education. This was closely followed by *mentoring programs for young carers*, particularly those targeting young carers to transition into further education and/or employment (37%).

271 respondents also left comments that broadly support the direction of the workshops, with many people telling us that young carers need to be able to easily and discreetly access the support they need.

4.4 INFORMATION AND COMMUNITY AWARENESS

INFORMATION

Proposed Outcome

Carers have access to information when they need it to support them

The process to date suggests that the focus for reform should be on embedding information for carers in the systems and services they use reducing the need for carers to search for information themselves. Critically, this must include mainstream services.

If successful, there will be more places where carers will naturally find information that is relevant to them or have information provided as a routine part of service delivery.

The short list of projects that were determined by the workshops as being achievable and likely to make an impact is as follows:

- **Online information** - coordinate and link-up on-line carer information including through options such as a distinctive carer link on all relevant websites.
- **Peer support networks** - enhance and ensure sustainability of carer peer support networks across NSW. Ensure that information about support groups is available in online resources.
- **Strengthen the role of medical practitioners** and other professionals in linking carers to information and support at the earliest possible opportunity.
- **Web based applications** - mobile and tablet applications and digital applications (eg widgets) that link carers to services and information, particularly in their local community.
- **Government service delivery** leading by example to provide quality information and responsive services to carers as part of a commitment to customer service.

Other ideas considered to have merit were listed as:

- Online support groups - fund/ support carers to moderate more online support groups and chat rooms for different types of carers.
- Health/ Support Coaches for carers - to ensure follow-up advice and support is available at particularly difficult and vulnerable times.
- Carer buddy system - pairs carers or groups of carers and supports individuals.
- Disease or condition-specific organisations – fund to provide information and support to carers.
- Technology training - programs to assist carers to become more digitally and technologically savvy.
- Singular carer website/database - bringing together current Health, FACS, NGO, and community-based information.

HAVE YOUR SAY

41% of respondents think *carers need to get information and support at the earliest possible opportunity*, including when contacting medical staff and organisations specialising in information about the care recipient. A further 21% also think *government agencies need to provide information and services that better meet the needs of carers*.

288 respondents also left comments broadly supporting the direction of the workshops. Many respondents made the case that carers are all different, will need information at different times and in different formats and that information needs to be culturally sensitive.

COMMUNITY AWARENESS

Proposed Outcome

The general community understands the role of carers

The process to date suggests that the focus for reform should be on using positive stories about caring to raise public awareness.

If successful, more people would understand the pressures on carers and what they are able to do to assist carers and the people they care for. This would mean carers feel more welcome in their communities, get greater support from colleagues, friends and family and spend less time explaining their needs.

The 'short list' of projects that were determined by the workshops as being achievable and likely to make an impact is as follows:

- **High profile carer ambassadors and expanding carer awards** to focus on organisations and workplaces as part of carer recognition measures.
- **Community events to raise awareness** - work with media partners to raise the profile of carers in the community including through events to attract community and media attention.
- **Enhance Carers Week** – introduce new events and community activities that raise community awareness of carers throughout the year.
- **Carer public relations program** - to better coordinate carer awareness programs and events, including school-based programs.
- **Mainstream media** - investigate ways to include more carer stories and carer perspectives in the mainstream media, including in local papers, in TV dramas and other television programs, and via downloadable videos.

Other ideas that were considered to have merit were listed as:

- Carer Passport - introduce a carer passport or identification card.
- Media industry carer advisory panel – establish a panel to provide advice on carer promotion and advice on successful strategies.
- Colour for carers (like the pink ribbon campaign).
- Carer media campaign - to address ignorance, stigma and prejudice associated with carers. Possible theme could be 'Carer Aware', with the key message of 'hope'.
- Partnerships for awareness raising - based on the UK Sainsbury model, partner with a major supermarket to establish a Healthy Living and Carers program.
- Education - systematically add carer content to course curriculum for all students in the health, welfare, education, and community service fields. Importantly this should include doctor and social work training.

HAVE YOUR SAY

42% of respondents think mainstream media coverage of carer stories, including newspaper, radio, television and online is the most important way to raise community awareness of carers. Almost 29% of people think media partners should develop innovative ways to raise the profile of carers in the community.

There were also 234 comments left which broadly support the direction of workshops but the largest number of comments questioned what direct benefit carers would see would from raising their profile in the community, with some people suggesting that instead the media could be used to teach people how to offer practical support to carers.

4.5 CARER ENGAGEMENT

Proposed Outcome

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

The process to date suggests that the focus for reform should be on making it easier for services and local decision makers to get carers' views on matters that affect them.

If successful, it would be easier for service providers and carers to be partners in care and communicate well, and would facilitate local services seeking the views of carers about how services and processes are designed so that they are easy to use.

The 'short list' of projects that were evaluated by the workshops as being achievable and likely to make an impact is as follows:

- **Partners in Care:** implementation of tools that have been evaluated as fostering effective partnerships between service providers and carers.
- **Carer Engagement in decision making:** development of a framework to make it easier for carers to be engaged in decision making (including government decisions) - a continuum of engagement from direct service delivery at the local level (i.e. partners in care) through to consultation on policy development.

Other projects that were considered to have merit were:

- Ongoing promotion of NSW *Carers (Recognition) Act 2010* and Carers Charter across public sector agencies
- Training and support for carers to facilitate involvement in consumer /community consultation and advisory committees
- Inclusion of carer representatives on consumer/community engagement committees
- "Carer Champions" and "Carer Officers" in different settings (government, non-government and business organisations). Embed carer engagement strategies into other policies
- Tool-kits for carers to become more empowered
- Carer Identification - mechanism to facilitate transfer of information within and across settings (eg social → health; General Practice → hospital system).

HAVE YOUR SAY

More than half of all respondents (52%) think the most important solution to engaging carers is to *involve carers in the planning and delivery of frontline services to their loved one*. As well as this, a further 23% of all people think that *training and support for carers to have input into programs and policy at the local or statewide level* is important.

215 people left comments broadly supporting the direction of the workshop. The most commonly made comments told of personal experiences of engagement and included information about what carers consider to be effective engagement i.e. they were listened to.

4.6 IMPROVING THE EVIDENCE BASE

Proposed outcome

Quality data and research about carers is available to inform policy and practice.

The process to date suggests that the focus of reform should be on better use of the carer information we have so that we understand better what makes a difference to them.

While there are gaps in research, there is a lot of information (qualitative and quantitative data, world-leading Australian academic research and extensive “grey literature”) about carers that we could use and share more effectively.

The short list of projects that were evaluated by the workshops as being achievable and likely to make an impact is as follows:

- Improving carer identification and analysis in data collection and reporting, by including basic (possibly standardised) carer questions in major surveys and forms (including, for example, health, employment, Seniors Card).
- Expanding interest in carer research and knowledge of good practice – for example by investigating opportunities for students placements with professional associations relevant to carers.
- Using key surveys (eg Carers NSW Biennial Carers Survey) to ask questions that tell us how carers are doing.

Other projects that were considered to have merit were listed as:

- Scoping the development of a ‘carer clearinghouse’ to effectively manage and share the information we already have on carers. (This was acknowledged to be a large and long-term project).
- Investigation of possible ways to work with existing online (and offline) research communities and networks about carers.
- Leveraging of existing research partnerships to trial carer initiatives and research, eg between universities and government agencies.

HAVE YOUR SAY

This focus area was not included in the *Have Your Say* online survey, but the analysis of the 2,362 survey responses provides valuable evidence in itself.

4.7 ABORIGINAL COMMUNITIES

Proposed Outcome

Respect for caring in Aboriginal communities

The process to date suggests that reform should focus on strengthening the position of Aboriginal people who are caring for multiple family members. Aboriginal carers are more likely to be caring for people of all ages and managing other pressures affecting their families.

If successful, this work would support those people in all their efforts to keep their families strong, and respect their culture and their caring.

What is caring like?

Aboriginal people care for each other, but don't think of themselves as "carers". Caring in Aboriginal communities is defined by strong family, kinship and culture. Many carers care for multiple family members, often through informal care arrangements and across a range of different health and other issues (including juvenile justice and out of home care). Caring also crosses generations.

Aboriginal carers need to be experts on multiple issues and engage with multiple organisations. Information is hard to find, and is mainly through word of mouth eg carer groups, yarn ups, friends and family. Aboriginal carers worry about emergencies and the future. Transport, housing and respite are also key issues for Aboriginal carers and communities.

The 'short list' of projects that came from the workshops and were discussed in more detail because they were achievable and likely to make an impact is as follows:

- Emergency planning and planning ahead for Aboriginal carers.
- Aboriginal carer 'yarn ups' to increase Aboriginal carers access to information.
- Increasing service provider's awareness of Aboriginal carers and culture – so they engage with carers, understand the importance of Aboriginal family and develop relationships, trust and respect.

Other ideas that were considered to be important were listed as:

- Multiple and key points of access to information provided in different formats to suit different carer needs eg through information technology and word of mouth.
- Information and solutions are localised so they are relevant to the community.
- Information and support for carers when they are no longer in the caring role.
- Transport – effective cost structures, criteria and rebates that reflect carers needs.
- Culturally appropriate respite.

HAVE YOUR SAY asked two questions of Aboriginal survey respondents:

What is good for Aboriginal carers?

- 36% of Aboriginal respondents said that support from services and within communities is good for Aboriginal carers, with specific reference to the need for flexible services.
- Being able to make decisions about caring was most important to 28% of Aboriginal respondents.

What one thing could make things better for Aboriginal carers?

- More than 45% of Aboriginal respondents referred to the *need for more support*, specifically help and assistance, advocacy and information about available services.
- 17% of Aboriginal respondents also think that care workers should understand Aboriginal culture, be non-judgemental, respectful and listen to carers.

5 Emerging solutions

EMPLOYMENT

5.1 Employers for Carers Network

"I have been extremely lucky where my employer set me up at home...If I didn't have this support from my employer, I would not be working and my son wouldn't be attending to all the therapies he does as I basically work to just pay for his needs". (HYS survey #1164)

Employers for Carers would be a network of leading employers committed to championing better employment outcomes for carers. If successful, Employers for Carers would assist more carers to sustain work and caring and give member organisations access to the valuable skills of carers as employees.

The network would be based on a successful model in the United Kingdom. Specific activities may include:

- sharing best practice in recruiting and retaining carers;
- promoting the use of existing workplace flexibility to help carers balance work and family;
- showcasing to carers (not in work) how member employers are able to accommodate their needs; and
- development of HR tools to assist employers to understand employees who are carers.

5.2 Recognising Carers Employment Skills

"My prospects for work looks gloomy and I have under 50,000 dollars in super. You can't go to a job interview and say I've been tube feeding my son for 19 years but I want to be a great school teacher" (HYS survey #566)

On discussion with partners, the Recognition of Prior Learning idea for carers has been expanded to encompass employment skills more broadly. The Recognition of Carers Employment Skills project would assist carers to identify the skills and knowledge gained through their caring role and from other life experiences. It would help them to explore job opportunities and options for further training including getting recognition towards a qualification. The project would focus on how caring can be used to demonstrate skills for a broad range of professions not only work in paid care roles.

Specific activities could include:

- development of an app that maps the daily tasks of carers to competencies used in job descriptions or training courses; and
- outreach to groups of carers wanting to work around options to use flexibility in the training system or to find a willing employer.

5.3 Public Sector Carers

This initiative would assist public sector agencies to better understand the nature of their workforce by including questions in workforce surveys about employees with caring responsibilities and incorporate carers in workforce diversity and sector reform strategies.

HEALTH AND WELLBEING

5.4 Medicare Locals

“Carer aware health services – are ones that ask the question ‘how are you going’”. (HYS survey #1858)

This project would work with Medicare Locals to improve the capacity of general practitioners and other primary health care professionals to work with carers.

Specific activities may include:

- getting information to front line health and community care professionals about the health issues carers experience;
- creation of opportunities for practice nurses to play a greater role in engaging patients with carers;
- embedding relevant information in the IT systems and protocols used in primary care;
- building carers’ knowledge and skills to effectively communicate their health needs with health professionals and services;
- tools to create care plans for carers and make best use of Medicare items; and/or
- development of integrated health and social models of care that consider and respond to the health and wellbeing needs of carers.

5.5 Convenient health checks for carers

“Balancing full-time work, family and carer responsibilities doesn’t leave much time for looking after your own health and well being and I get sick of hearing that I should do so. I am well aware that I need to but there’s insufficient hours in the day and much of the support doesn’t take account of this fundamental lack of time”. (HYS Survey #810)

This project would seek to explore ways of incorporating the provision of health services to carers within integrated care models and in other settings convenient to carers. As more integrated health care models are developed, it may be possible to also provide basic services to carers, particularly screening and monitoring.

Specific activities may include:

- Promotion of health checks or provision of health information in other health settings. For example:
 - Carer health in telehealth models of care, particularly where monitoring equipment is provided in people’s homes.
 - Checking carer health as part of integrated care model in residential aged care or other settings.

5.6 Individualising carer respite

“... giving carers options as to how they could use their support allocation. For example: sometimes just having someone to come and do housework, child minding, just giving me a break at home would help...” (HYS Survey #902)

This project would seek to provide carers and the people they care for with the greatest possible flexibility in the way services and supports are provided to give choice and control. This would make it easier for carers to stay in work and participate in the community in ways that would improve their wellbeing. This would encourage a move away from block funding of respite toward individualised and flexible approaches.

This agenda is consistent with reforms to the provision of disability services in preparation for the National Disability Insurance Scheme. This may include exploring whether this work can be applied in other service sectors.

5.7 Carer support groups

“As a carer I found participating in peer support groups (both formal education and information groups and groups providing joint social activities for both myself and the person I cared for) the best support for my wellbeing as I was interacting with people who were in the same situation as myself and who UNDERSTOOD what I was going through. It stopped the isolation I found overwhelming once I was forced to leave my employment. I could not have survived my full-time caring role for 7 years without them”. (HYS survey #687)

This work would seek to create links between the many programs that support peer support groups for carers. It may be possible to expand carers’ access to peer and group-based support across programs and provide more opportunities to connect and exchange peer-based advice and information with less social isolation. Carer health and wellbeing would be improved through social inclusion and improved connections with other carers in the local community.

Specific activities could include:

- building of a comprehensive directory of carer support groups across NSW for use and integration in relevant information portals referral pathways;
- exploring and expanding online models of peer support and carer support group models;and/or
- review of current eligibility and funding criteria with a view to decrease restrictions on carer participation/involvement, especially for CALD and rural and remote carers.

YOUNG CARERS

5.8 Young carers are supported at school

“Flexibility is needed in how education and training is delivered. I am also a student. I rely on being able to do most of my study online however I am still mandated to attend classes in person. This is very stressful when I’m trying to juggle carer responsibilities (and work).” (HYS survey #1797)

This work would seek to embed awareness about carers within strategies to improve student wellbeing in schools. If successful, it would make young carers more confident about disclosing their status as carers and revealing how it impacts on their education. This should make it easier for schools to respond to needs for extra assistance or flexibility so that caring does not impact on young people’s achievement. This work could be extended to independent schools and tertiary institutions such as TAFE and universities.

5.9 Young Carer Mentoring

“...person to person contact is vital for young carers - to share experiences and be truly recognised and supported and be understood at a personal day to day level. Apps and websites etc can be useful back ups but should never be instead of personalised connection and person to person support.” (HYS survey #1337)

Mentoring would offer an informal source of social and emotional support to young carers who may be trying to manage and balance the demands of their education with their caring responsibilities. This work could be achieved by specifically targeting young carers within existing mentoring programs or adding mentoring components to existing work with young carers.

The program could be based on a number on current models such as the Australian Indigenous Mentoring Experience or the Brightside youth mentoring model.

5.10 Mobile Application (App) for Young Carers

“ Young carers themselves say they need information that is easier to access and designed in a youth friendly way.”. (Young carer at the – Carers Strategy Young Carers workshop)

An app designed by young carers would create a virtual space for young carers to receive information and provide peer support to one another. This may also be an easier way for young carers to ‘self identify’ and to connect with supports and services.

CARER INFORMATION

5.11 On-line information and applications

“Need one central repository for information. At the moment it is very spread out. A mobile phone app or web site would be good for this.” (HYS survey #1703)

This project would seek to embed information and links for carers in the range of websites carers would use on a regular basis. This may include services like the national healthdirect sites, condition-specific websites, local government and websites of the private sector. This would also make it easier for intermediaries like libraries and neighbourhood centres to find information for carers who are not on the web.

Specific initiatives may include:

- development of tools and devices to make existing information more integrated and easily available;
- a distinctively branded carer link or tab, so that it is readily recognisable to carers and is used consistently across relevant websites;
- ensuring the inclusion of links to existing carer information and websites;
- work with major websites to ensure the quality of targeted carer information; and/or
- improving access to reliable health information and advice – designed for carers when they need it most (eg. “Caring for someone” information on websites; collaboration between Carers NSW and HDA to create a downloadable carer health & wellbeing support pack).

COMMUNITY AWARENESS

5.12 Media Campaigns

“...greater mainstream media coverage of carer stories. Media partners are well placed and experienced in communication strategies which can spearhead increased community awareness.” (HYS survey #1775)

This project would work with the media industry or public relations experts to coordinate programs and events that raise awareness and understanding among the general public.

Specific activities may include:

- the establishment of a unique community event/s likely to attract media attention;
- carer branding, including the adoption of an easily recognisable symbol and or colour for carers;
- working with television networks and script writers to include more carers in Australian television;
- investigation of options to feature carers within programming, including documentaries, reality TV and existing shows such as *Australian Story*; and/or
- creation of downloadable videos.

5.13 Enhance Carers Week

This project would reform Carers Week in NSW to have a greater impact on community awareness and understanding.

Specific activities may include:

- introduction of new events and community activities to raise community awareness of carers;
- use of Carers Week as a culmination of events and activities held over previous weeks;
- a major focus on schools; and
- Small grants to allow local communities or organisations to host additional events.

ENGAGEMENT

5.14 Engaging Carers in decisions that affect them and the people they care for

“A framework is the first port of call in order to “legitimise” the needs of carers. In addition all frontline services need to include consumers and carers in a meaningful way in service planning.” (HYS survey #808)

This project would develop tools to make it easier for government agencies to involve carers in decisions, particularly through access to carer representatives trained by non-government organisations. This would support compliance by all government departments with the NSW *Carers (Recognition) Act 2010*.

Specific activities could include:

- maintenance of a database of trained carer representatives able to participate in local decision making;
- refinement and promotion of staff training modules about carers; and/or
- provision of training and support for carers to facilitate their involvement in consumer engagement/advisory committees.

5.15 Partners in care

“Carers are wonderful health care monitors, practitioners, and data collectors however health staff are missing out on this vital information when they do not engage carer in the planning and delivery of services to the person they support. Carer expertise & knowledge is the key to gaining a thorough health needs assessment and for effective discharge planning - health practitioners should be falling over themselves to engage carers (when the relationship exists).” (HYS survey #479)

This proposed solution would emphasise the importance of recognising that carers are an integral and critical part of the care team and should be consulted in the development of care plans for the person they care for (to the extent they choose).

This may include:

- a project to support the participation of carers of people with disability - so that they can understand and realise the possibilities (for themselves and the person they care for) offered by the new person-centred and individualised models of support (eg NDIS);
- Consultation with carers during the development of models of care by health and disability services;
- Development of practical care-planning tools that acknowledge carer knowledge and expertise about the person they care for;
- Training for frontline staff in practical strategies and the use of care-planning tools that assist them to engage with carers; and/or
- Use of practical strategies to reduce barriers to health literacy, such as ensuring carers are targeted in wider health literacy initiatives, so that carers from a variety of backgrounds can engage in care planning.

IMPROVING THE EVIDENCE BASE

5.16 Improving carer identification in data collection and reporting

This project would develop suggested standard carer data items that could be incorporated into surveys and reports.

Specific activities may include:

- development and trial of suggested questions/data items – including ways of asking questions about caring using everyday language (to pick up people who don't identify with the term "carer");
- Targeting of key areas (health, employment, seniors card) where data items could be included; and/or
- Promoting the value of asking information about carers.

5.17 Carer-focussed student placements

This initiative would involve the development of partnerships between university faculties and professional associations and other relevant bodies to promote exposure of students (eg medical, social work) to carers issues.

5.18 Utilising key surveys to measure carer outcomes

This initiative would maximise the potential of some key existing surveys to regularly measure how carers are doing. These collections include the biennial carers survey undertaken by Carers NSW. Other peaks and organisations may also be able to include carer questions in similar stakeholder surveys.

ABORIGINAL COMMUNITIES

5.19 Planning and information for Aboriginal carers

This initiative would support Aboriginal carers to plan for times of emergency and enable them to access information about services and support when they need it in ways that suit them.

“You need a portfolio on what they need. Then if anything happens someone can step into your shoes.” (Aboriginal carer at an Carers Strategy Aboriginal workshop)

Emergency care plan

Support Aboriginal carers to develop practical strategies which could be activated in times of emergency. This would involve developing a culturally appropriate care plan template with important information prompts and which can be tailored for individual needs.

Specific activities may include:

- working with relevant partners/key stakeholders to design care plan template; and/or
- development of strategies to actively communicate and promote this resource to Aboriginal carers in ways which are culturally appropriate and relevant to their community.

“I lived in the dark. I didn’t know they (services) existed.” (Aboriginal carer at an Carers Strategy Aboriginal workshop)

Aboriginal carer ‘yarn ups’

Carer yarn ups would be broad in focus, and not about a specific illness or disability, recognising that Aboriginal carers support multiple family carers with different needs. If successful, carer yarn ups would provide information to Aboriginal carers through word of mouth which is a preferred method for many carers.

Specific activities may include:

- identification of key stakeholders such as Aboriginal carers, peak agencies and existing Aboriginal carer networks;
- Mapping of existing carer yarn ups and analysis of their criteria for success;
- Linking existing carer support group databases with the Health Direct database to increase Aboriginal carers’, services’ and care workers’ awareness of existing yarn up groups;
- development of strategies to initiate carer yarn ups where they are needed; and/or
- promoting carer yarn ups to Aboriginal carers.

5.20 Planning ahead for Aboriginal carers

This initiative would assist Aboriginal carers to have culturally appropriate and locally relevant information and advice to help them plan ahead eg how to complete wills and information about typical funeral costs.

6 Appendices

Appendix A: Carers Strategy Workshops

Appendix B: Map of emerging solutions

Appendix A: Carers Strategy Workshops

Employment

Workshop1	4 December 2013
Workshop 2	16 December 2013

Carer Health and Wellbeing

Workshop 1	5 December 2013
Workshop 2	7 February 2014

Young Carers- Education

Workshop 1	26 November 2013
Workshop 2	16 December 2013

Carer Information and Community Awareness

Workshop 1	12 December 2013
Workshop 2	5 February 2014

Carer Engagement

Workshop1	22 November 2013
Workshop 2	6 December 2013

Improving the Evidence Base

Workshop 1	12 February 2014
Workshop 2	27 February 2014

Aboriginal Carers

Workshop 1	6 February 2014 (Dubbo)
Workshop 2	4 March 2014 (Redfern)
Workshop 3	12 March 2014 (Mt Druitt)

NSW Carers Strategy Collective Vision: We acknowledge the importance of carers in NSW and that they should be respected and valued, with the same rights, choices and opportunities as others and, importantly, the time and energy to care for themselves. To achieve this vision we have solutions that will empower carers in these areas.

What are we aiming for?	The Emerging Strategy solutions
Employment Carers have choices and opportunities to participate in paid work	5.1 Employers for Carers Network 5.2 Recognising carers employment skills 5.3 Public Sector Carers
Health & wellbeing Carers experience good health and wellbeing	5.4 Medicare Locals 5.5 Convenient health checks for carers 5.6 Individualising carer respite 5.7 Carer support groups
Young carers Young carers have choices and opportunities to realise their aspirations in life	5.8 Young carers are supported at school 5.9 Young carer mentoring 5.10 Mobile application (App) for young carers
Information and Community Awareness Carers have access to information when they need it to support them The community understands the role and life of carers	5.11 On-line information and applications 5.12 Media campaigns to raise the profile of carers in the community 5.13 Enhance Carers Week
Engagement Carers are recognised and actively involved in decisions that affect them and the people they care for	5.14 Engaging Carers in decisions that affect them and the people they care for 5.15 Partners in care
Evidence Base Quality data and research about carers is available to inform policy and practice	5.16 Improving carer identification in data collection and reporting 5.17 Carer-focussed student placements 5.18 Utilising key surveys to measure carer outcomes
Aboriginal Communities Aboriginal people who are caring for multiple family members are supported	5.19 Emergency planning and information for Aboriginal carers 5.20 Planning ahead for Aboriginal carers



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