

# NSW CARERS STRATEGY 2014–2019





Carers support people to live independent lives, to remain in their own homes and in their own communities. This care is fundamental to family life and our community wellbeing.





## Foreword

In our lifetime, most of us are likely to either provide care to a family member or friend, or to need care ourselves. The work that unpaid carers do is essential to the wellbeing of our society and economy.

There is research however, that shows that carers have much lower health and wellbeing than other demographic groups.

Improving support for carers should concern the entire community.

The NSW Government's vision for the more than 857,000 carers in NSW is that they are supported to participate fully in their own social and economic life. We want them to be healthy and live well.

The NSW Carers Strategy is a five year plan to improve the position of carers in NSW. The strategy will be implemented by government, non-government organisations and private businesses in new partnerships designed to deliver better services and support for carers.

Carers see themselves as ordinary people who would like the broader community to understand that caring is both rewarding and often challenging. It is important to unpaid carers that the care role is recognised by the community.

Carers deserve access to the kind of support that enables them to take responsibility for their own lives, including their caring duties and their health and wellbeing.

The NSW Carers Strategy is the result of an extensive collaboration with more than 2,500 people, mostly carers, who shared their ideas on how government agencies, business and community groups could better support carers.

The strategy contains practical approaches that we hope will make a real difference in carers' lives, not only in the care they provide, but in important areas such as employment, education and health and wellbeing.

The NSW Carers Strategy builds on what the NSW Government is already doing to raise awareness and recognition of the challenges carers face. It complements reforms in other areas such as disability, mental health, and ageing. It provides a broader context for the ongoing implementation of the *NSW Carers (Recognition) Act 2010*.

Thank you to our partners and to all the people who have contributed to the development of the strategy and those who will be working with us to implement it.

**The Hon. John Ajaka MLC**  
Minister for Ageing  
Minister for Disability Services

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# Carers in NSW

Carers provide ongoing unpaid support to people who need it because of their disability, chronic illness, mental ill-health, dementia or frail age.

Carers support people to live independent lives, to remain in their own homes and in their own communities. This care is fundamental to family life and our community wellbeing.

Unpaid care is critical to the sustainability of our health and community services systems. It would cost over \$40 billion to replace the hours of care provided by unpaid carers in Australia (*The Economic Value of Informal Care in 2010*, Access Economics 2010).

Carers are as diverse as the rest of the community and cultural factors impact on caring. People from culturally and linguistically diverse backgrounds may have different expectations about how and who will provide care.

Caring is an important cultural value for Aboriginal people. Aboriginal concepts of care are based on the notion of family obligations, so Aboriginal carers often take on a large caring role. Poorer health and intergenerational disadvantage have also led to a higher proportion of Aboriginal people relying on unpaid care. Aboriginal carers are more likely to be caring for children who cannot live with their parents, as well as family members who are ageing or have a disability, chronic condition or mental illness.

Recognition of carers is gradually improving. For example, the NSW *Carers (Recognition) Act 2010* and the NSW Carers Charter place obligations on NSW Government agencies to recognise and value carers and ensure carers are consulted on policy matters that impact on them. The Act also established the NSW Carers Advisory Council as the main advisory mechanism to the Minister on carer issues.



ABS 2012, Disability, Ageing and Carers  
Australia, NSW April 2014

# Development of the NSW Carers Strategy

## Engagement agencies



## Feedback



## Timeline for the development of the NSW Carers Strategy



*We're working together in a co-design model which is fantastic because we're bringing together all the stakeholders... corporate and government agencies and also the voice of carers which is really important...*

Cheryl Koenig, Carers Advisory Council member

## More information

Information about the strategy can be downloaded along with its background and development at [www.carers.nsw.gov.au](http://www.carers.nsw.gov.au). It includes the following resources:

- Developing the NSW Carers Strategy — *Creating Innovative Solutions with Carers Background Paper*
- Developing the NSW Carers Strategy — *Have Your Say online consultation report* (March 2014)
- NSW Ministerial Carers Strategy Summit Background Paper.





# NSW Carers Strategy 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
<b>Employment &amp; education</b>	<ul style="list-style-type: none"> <li>• Increase the use of existing workplace flexibility by carers and their employers</li> <li>• Enable carers to recognise the skills and expertise they bring to employment and training</li> <li>• More young carers receive support at school to transition to further education and employment</li> </ul>	<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>
<b>Carer health &amp; wellbeing</b>	<ul style="list-style-type: none"> <li>• 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</li> </ul>	<p>Carers experience good health and wellbeing</p>
<b>Information &amp; community awareness</b>	<ul style="list-style-type: none"> <li>• Embed and improve information for carers in the trusted systems they frequently use</li> <li>• Create positive media campaigns that portray carers as real people</li> <li>• Increase the number of people with an understanding of carers lives</li> </ul>	<p>Carers are able to easily access information when they need it</p> <p>Carers feel the broader community understands their experience</p>
<b>Carer engagement</b>	<ul style="list-style-type: none"> <li>• Continue to improve the ways we involve carers as partners in the care delivered to their loved ones</li> <li>• Greater involvement of carers in local decisions about the design and delivery of services</li> </ul>	<p>Carers are involved in decisions that affect them and the people they care for</p>
<b>Evidence base</b>	<ul style="list-style-type: none"> <li>• Better use is made of the available data and research to create evidence that will shape policy and programs</li> </ul>	<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.

## The five focus areas



# 1 | Employment and education

## Outcomes

Carers have choices and opportunities to participate in paid work

Young carers complete school and transition to further education and employment

One of the highest priorities for carers in NSW is combining caring and paid work. Employment brings financial security, social connection and improves personal well being. Carers also bring significant skill and expertise to workplaces.

Many workplaces offer carers flexibility to help them balance work and care. Some employers promote the use of flexibility as a strategy to recruit and retain carers. In most workplaces, however, carers' needs for workplace flexibility are not commonly discussed with their managers and colleagues.

The NSW vocational education and training (VET) system offers a range of flexible training options that can assist carers. The NSW Government's Smart and Skilled reforms will enhance the VET system by enabling eligible carers to access funded training to gain work skills, up-skill or re-skill to enter the workforce. Under Smart and Skilled, students will have flexibility and choice in training.

For young people, successfully finishing school is critical to attaining higher education and/or employment opportunities. Schools are committed to providing a supportive environment for all students, including those with caring responsibilities, and are able to offer flexibility and support. Young people will be more likely to disclose that they are carers if their school community has a strong focus on the wellbeing of all students, and is sufficiently informed about young carers.

The focus of reform for the next five years will be to:

- increase use of existing workplace flexibility by carers and their employers
- enable carers to recognise the skills and expertise they bring to employment and training
- support more school aged young carers to successfully transition from school to further education and employment.

**105,000**  
carers under the age of 25



The first commitments to progress this work are:

### 1.1 Network of employers to champion carer friendly workplaces

This project will seek to develop a network of progressive employers across diverse industries to champion better employment outcomes for carers and promote a business case for recruiting and retaining carers. The network will share best practice, promote flexibility and showcase employers that have strategies to assist working carers and carers who are not in the labour market.

#### Who's involved?

The NSW Government, working with employers, the Australian Government and associations representing carers and employers. The NSW Government will participate in the network as an employer.

*I have been extremely lucky 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 all the therapies he does as I basically work to just pay for his needs.*

‘Have Your Say’ survey respondent

### 1.2 Recognising carers' skills

A resource tool will be developed to assist carers to understand how the skills, knowledge and experience they have built up as carers can be used to gain employment. The tool will help carers to describe their daily activities in ways that can be used in job applications or in getting recognition for training. The tool will encourage carers to consider a broad range of professions, not only paid caring roles.

#### Who's involved?

The Department of Family and Community Services, Department of Education and Communities (State Training Services) and the NSW Community Services and Health Industry Training Advisory Body are jointly leading this project.

### 1.3 Carers working in the NSW Government sector

The NSW Government is the largest employer in NSW. The NSW Workforce Diversity Framework and government sector workforce surveys will incorporate a carer focus. The NSW Government will also explore opportunities to incorporate a carer focus into existing government sector guidelines and policies. This will influence employment practices across the NSW Government sector and help agencies to meet their obligations under the *NSW Carers (Recognition) Act 2010*.

The Department of Family and Community Services will also continue its work to lead the implementation of the *NSW Carers (Recognition) Act 2010* across government and other public sector agencies in NSW, in accordance with provisions under the Act.

## Who's involved?

NSW Public Service Commission, NSW Industrial Relations and the Department of Family and Community Services.

### 1.4 Support for carers at school

The Department of Education and Communities is committed to providing a safe, supportive and inclusive environment for all students and staff. In 2014 the Department is developing the Wellbeing Framework, which will include a suite of resources focused on universal and more targeted approaches to support the wellbeing of students, staff and community, including those who have a caring role, to enable them to engage successfully in their schooling journey.

Schools will be supported to identify and respond to the wellbeing of young carers in their community through strategies such as:

- promoting the value of caring in the school community
- providing information, resources and professional learning for staff about young carers
- recognising young carers' changing needs on their education pathway.

## Who's involved?

The Department of Education and Communities is leading the project.

### 1.5 Young carer mentoring

Facilitate a cross agency project roundtable to develop a strategic approach to increasing young carers' access and focus in existing youth mentoring programs.

## Who's involved?

The Office of Communities is leading this project in collaboration with Carers NSW, the Department of Family and Community Services and other partner agencies.

**Young Carers have lower education participation and attainment rates than their peers**

Young people



Young carers



ABS 2012, Disability, Ageing and Carers Australia, NSW April 2014

## A job is life changing



Wendy and Rob Harris care for their 16 year old daughter Laura, who has a disability. This is Wendy's story.



“I care for my profoundly disabled 16 year old daughter Laura who can’t walk unassisted and is totally dependent on me and my husband Rob for all aspects of her care, 24 hours a day. Laura has multiple conditions and very complex care needs, but we wouldn’t change her for the world. Everything we do is for Laura.

I found being a full time carer and not having a job was extremely socially isolating and financially challenging. Financial struggles and a life without friends led me down a path of depression and low self-esteem. At my lowest point I spent days sitting on the lounge eating ‘rubbish’ food. When I realised it was almost time for Laura to arrive home I’d have a quick wash and put a smile on my face ready to pretend everything was fine. But it wasn’t – I was overweight, lazy and miserable.

One day I woke up and decided this wasn’t the life I wanted. I wanted to work but didn’t know how I could fit it in so I began by looking at training options. My local adult education centre held courses but they didn’t finish early enough for me to get home in time for Laura. Luckily I spoke to staff and was surprised when they totally understood my time constraints and allowed me to start a bit earlier and have a shorter lunch so I could fit study in with being there for Laura.

After I completed my studies, I applied for a number of jobs unsuccessfully. There were so many rejections. I reached a point, when I’d just applied for a part time position at Attorney-Generals, when I wondered what the point was of continuing to try to find work.

Once again I explained my caring role and responsibilities at the very beginning so they were aware that sometimes I might need time off to attend to Laura, and while Laura is, and always be will, my priority, I would also be committed to my job.

Much to my surprise, they told me they are committed to employing carers and actually adhere to a Carers Charter. I’ve ended up not just with a job, but with a job I love and am fully supported in. My employers have always shown interest in my wellbeing (asking if I’m okay and how Laura is) and career progression (I was one of 10 people across the Department chosen to complete a certificate IV related to my job). I’m supported to take time off when Laura needs me and in return I’m willing to work more at other times to compensate. When overnight travel is required, I know I can say no if I can’t rearrange Laura’s care. The Department was so proud of my NSW Carers Award they encouraged me to attend the Awards ceremony at Parliament House and published an article about me in the Department’s newsletter.

I got that job two years ago. I’ve now lost weight and take great care in my personal appearance again. I’m much happier, have a group of friends to socialise with and financial security which has allowed me to give Laura adventures and things I couldn’t before. Finding a job created a major change in my life but also in my family unit and in my ability to give lifelong care to my daughter. I realise that taking that first step isn’t easy but it’s worth taking and could result in the most rewarding thing you ever do.”

Wendy Harris, 2014

## 2 | Carer health and wellbeing

### Outcome

#### Carers experience good health and wellbeing

Carers know that their own health and wellbeing is important but say that it can be difficult finding 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.

Carers say that not being able to monitor their own health is a major source of stress. Carers are regularly taking people they care for to health services, but then do not have time to get to the services they need for themselves. Carers appreciate health professionals who also ask about their wellbeing and make it easy for carers to get some of their own health needs met at the same time as those they care for.

#### Studies show that carers are more likely to experience physical and mental ill health and disability than the general population

Studies include: *The Wellbeing of Australians – Carer Health and Wellbeing*, Deakin University

Carers value the support services available to them and the people they care for. Flexible services that can be tailored to each client's circumstances have the greatest impact for carers. Service flexibility helps carers to manage competing demands on their time, making it more possible for carers to look after themselves, have a job and maintain relationships.

Time with other carers can be a great help. Support groups for people caring for others in the same situation or with the same condition are helpful ways to exchange information and strategies. Peer support also creates social connections with people who understand the challenges caring presents. Carers are likely to feel better supported if they have the options to access support from a variety of means.

The focus of reform for the next five years will be to 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.

The first commitments to progress this work are:

## 2.1 Easier access to health care

This project will seek to make it easier for carers to use health care and health promotion services by:

- promoting and targeting existing flexible health screening and intervention programs to carers, including NSW Health *Get Healthy Information and Coaching Service*<sup>®</sup>, and community or workplace based health check programs (such as pharmacy health checks)
- finding ways for carers to access services when they are accompanying the people they care for
- raising awareness of carer health issues amongst service providers so they can better support carers to look after their health and wellbeing
- developing training and support to encourage carers to discuss their own needs with health professionals
- building linkages with the NSW Health Family and Carer Mental Health Program to raise awareness of support opportunities.

*Carers will need to have the time to engage with these services. Often they just have their heads down to get through the day in order to get everything done. These supports must fit into their current daily routines so as not to become something extra they have to do in their already busy day.*

‘Have Your Say’ survey respondent

## Who’s involved?

NSW Health and Carers NSW are leading these projects in collaboration with the Department of Family and Community Services, Healthdirect Australia, professional associations and other key partners.

## 2.2 Individualising respite and support services

As part of the reforms announced under *Ready Together* and in preparation for the National Disability Insurance Scheme (NDIS), funding for respite and other disability services will be available on an individual basis into the future. This will give people with disability greater choice and control, and will help them to develop a package of support that is more flexible for their carers and family members. Funding will move away from inflexible, block-funded services.

## Who’s involved?

The Department of Family and Community Services.

## 2.3 Carer peer support

Funders and providers of peer support programs for carers will be brought together to look at ways to extend the variety and reach of peer support programs in NSW. This will include:

- building a comprehensive database of carer peer support groups that can be used by telephone help lines, referral services, online service directories and app developers
- exchanging best practice facilitation for carer peer support
- seeking other opportunities to improve peer support by working together, particularly for small communities.

### Who's involved?

The Department of Family and Community Services and Carers NSW are jointly leading this project, with support from NSW Health, other peer support providers, and services funded under the Department of Family and Community Services Carers Grants program.



## 3 | Information and community awareness

### Outcomes

Carers are able to easily access information when they need it

Carers feel the broader community understands their experience

Access to good information helps carers enormously. Caring often starts suddenly and people need to quickly learn about the new needs of their loved ones. Throughout their caring journey people need information about services, resolving problems and getting personal support.

Carers get information from many places such as family and friends, GPs, online, community groups and libraries. Technology has made far more information available, but good information harder to find. Not everyone sees themselves as a carer or will think to look for carer specific websites and information.

*I lived in the dark. I didn't know they (services) existed.*

Aboriginal carer at NSW Carers Strategy workshop – Redfern, March 2014

Ideally, carers would find useful information in the places they normally go, perhaps through a single link or referral. Our aim is to redesign communication channels so that information reaches carers, rather than relying on carers knowing where to seek it out.

Carers see themselves as ordinary people and want the broader community to understand that caring is both rewarding and challenging. Many carers say that they want their role to be valued, but do not want to be seen as either saints or victims.

Greater community awareness is important to carers because it directly relates to the attitudes carers encounter every day. Carers want others to know enough about their lives so that it is easy to ask for assistance and be part of the community. Greater community awareness will also help people to seek support if they become carers.

Recognition of carers in the community has increased in NSW. Formal legislative recognition and public events have provided opportunities to make carers more visible in the community. Carers report greater recognition, but still do not feel that society values their caring role.

The focus of reform over the next five years will be to:

- 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.



The first commitments to progress this work are:

### 3.1 Media campaigns to raise the profile of carers

Media campaigns will be developed to improve public awareness and understanding of carers' lives, using a diverse range of carers' stories, preferably communicated through mainstream media. Events such as Carers Week and the NSW Carers Awards are platforms to reach the broader public. Targeted strategies may be developed for different sections of the community such as workplaces, educational facilities and retail outlets. These campaigns will also assist people who do not think of themselves as carers to seek support they may require.

*Carer stories should concentrate on positives but not make it as a fairy tale, all smiles and Hollywood ending. Be Aussie like, tell things as things are for the carer in focus, nothing is 100% good or bad, so do not make it seem so.*

“ ‘Have Your Say’ survey respondent

#### Who's involved?

The Department of Family and Community Services, Carers NSW and other partners.

### 3.2 Embed and improve information for carers

This project will embed information useful to carers into the trusted systems they frequently use. The information will be targeted to people who do not see themselves as carers and is likely to include:

- webpage tabs targeting carers, that will address common carer questions and link them to services
- embedding online search tools (widgets) for commonly needed services into condition-specific websites, drawing on and enhancing comprehensive databases like the National Health Services Directory
- providing carer content and enhancing referral options for large scale providers such as the services provided through Healthdirect Australia – After Hours GP Helpline and the Nurse Triage Service, to better address carer needs
- working with partners to improve existing service information for carers, for example, GP's who specialise in working with people who have an intellectual disability.

#### Who's involved?

Carers NSW and Healthdirect Australia are jointly leading this project, with support from the Department of Family and Community Services.



### 3.3 Young carer mobile application (app)

A new app will be developed by and for young carers to create an accessible and age-appropriate self-assessment tool for young people with caring responsibilities. The app will encourage young people to self identify as carers and to get the support that is right for them, when they need it. Additional functions and features will be considered for a possible second stage or upgrade of the app.

#### Who's involved?

The Department of Family and Community Services is leading this project in collaboration with Carers NSW (Young Carer program) and NSW Finances and Services (Apps4NSW).



### 3.4 Information for carers in Aboriginal communities

Culturally appropriate resources will be developed and promoted to Aboriginal carers. These resources will include information on services and supports as well as tools to assist carers to plan ahead and involve other family members in providing care. This will include:

- An emergency care and contacts template that carers can use to document key contacts for those they care for. The template can be shared with other family members to enable them to step in and assist with caring, and allow carers, who often have multiple caring responsibilities, to attend to other care or cultural responsibilities such as Sorry Business.
- Specific strategies encouraging Aboriginal people, including carers, to complete wills, powers of attorney and enduring guardianships with the NSW Government's *Get It In Black and White* campaign.

*Relationships and trust are important. I want your understanding and I want you to walk beside me.*

Aboriginal carer at NSW Carers Strategy Redfern workshop – March 2014

Resources will be developed and promoted in ways that they can be adapted to reflect local characteristics of individual communities.

#### Who's involved?

The Department of Family and Community Services is leading this project via a working party, which will include Aboriginal community partners; Aboriginal services funded under the Department of Family and Community Services' Carers Grants program (such as the Yarkuwa Indigenous Knowledge Centre); Aboriginal Affairs; NSW Department of Attorney General and Justice (NSW Trustee and Guardian); and key community agencies including Carers NSW, The Benevolent Society and National Disability Services (NDS).

*The rate of caring amongst the Aboriginal community of NSW is significantly higher than the non Aboriginal community (13.6% compared to 11.4%)*

ABS Census of Population and Housing 2011



1 in 8 Aboriginal people in NSW are carers

## You and I

Dolly is an Aboriginal woman who cares for her three grown up daughters who all have a disability. She accesses services from the Benevolent Society where Sharlene works as a coordinator.



Dolly Brown & Sharlene McKenzie

### Dolly

I'm from a big family and caring happens naturally in my family. It's a cultural thing with Aboriginal people. We keep an eye out for each other and the door is always open.

In every family there is a rock and that's where I come in. When I was working, my manager was very supportive however I had difficulty accessing services for my daughter Jemma. After our house burned down, Jemma was traumatised and also needing more care so I took it upon myself to be her full time carer.

Sharlene comes up with things unexpectedly. She has helped my family without me asking. She doesn't say much but it's just the look that says she's there for you. She doesn't fuss about with wanting to know why, what or how, she just does things.

Once I tried to thank her and she got very quiet. She didn't say anything but I got the feeling that she didn't want thanks and then she started to get emotional.

Personal contact from services means that they are there for you. LISTENING in capitals is the key. It also means it's not all in jargon – literacy is still an issue in my community. Being able to see an Aboriginal person and their body language is important.

I have learnt from Sharlene that I am human. I can get through my everyday. She has opened up a lot of doors for me and I know I am not alone.



## Sharlene

The most important part of my job is to make sure that Aboriginal carers and community have access to programs that address their needs in a culturally respectful way. I also create a deeper understanding of Aboriginal people through my work.

The aspect of my job that I find deadly is being able to contribute in a positive way to the day to day lives of the people in my community. I love the strong connection that I share with my community and find it very satisfying that I can fulfill my cultural responsibilities

When I first met Dolly she had spent a long period of isolation from services and I wanted to place some support around her to enable her to fulfill her caring role. I also wanted Dolly to be able to connect with other Aboriginal carers so they could support each other.

Most carers within my community do not recognise their caring roles because traditionally caring for family and other mob is something that has always been done. Often individuals care for multiple people with complex needs and across generations.

Traditionally, my community shares information and stories orally. I yarn about what is available to support them and I visit them in their homes so they can share their experiences with me. The ability to listen is a cultural strength and an essential part of the work that I do.

Dolly has taught me that Aboriginal carers are strong, resilient and committed to their caring roles. She has helped me give a voice to other Aboriginal carers. She has taught me about true mutual respect and how it is possible to bring about change in the lives of our fellow community members.



## 4 | Carer engagement

### Outcome

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

Carers are valuable partners in the delivery of services to the people they care for. Carers have knowledge and expertise that allow care plans to be tailored to individual needs and if involved, will improve the effectiveness of formal services. This requires carers to be involved in care planning and monitoring.

Actively involving carers in the design and delivery of services is likely to result in better outcomes. Carers are alert to simple and practical measures that may block access to service delivery or will make it easier for carers to be part of the care team.

The NSW *Carers (Recognition) Act 2010* recognises the role and contribution of carers in our community and to the people they care for.

The Act introduced the Carers Charter which provides direction to government and other public sector agencies (including those that provide a human service) about how they should treat carers and involve them in decision making. These obligations extend to ensuring, where appropriate, that carers are:

- engaged as partners in care, including the assessment, planning, delivery and review of services to the person they care for, and
- included in decision making through consultation.

The Act also establishes the NSW Carers Advisory Council to provide a voice for carers across NSW Government on strategic policy decisions that impact on carers.

A range of initiatives and reforms already exist to engage carers in decision making processes and the NSW Government is committed to building on these. Work is underway in health care settings to involve carers in patient care and service design and delivery. The person centred approaches we are taking in disability reform and preparation for the National Disability Insurance Scheme will also engage carers in decision making.

Over the last three years, the NSW Government has devolved decision making to a more local level to create a better relationship between services and their communities. Local decision making will be more likely to involve carers if there are simple systems for both services and carers to talk to one another.

The focus of reform for the next five years will be:

- to 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.

The first commitments to progress this work are:

#### 4.1 Partners in care – health care

Care planning tools will be developed that will make it easy for service providers to actively seek carer input into the care planning process. This will build on work being done by NSW Health that acknowledges the importance of carer expertise and knowledge (such as the Clinical Excellence Commission's Partnering with Patients Program and the community based palliative care reforms).

NSW Health is also developing an e-learning module for NSW Health staff called 'Partnering with Carers'. The module aims to raise awareness across the Local Health Districts of the importance of engaging with carers. It will give practical examples of ways staff can engage effectively with carers, including tools such as the TOP 5. TOP 5 is a simple process that encourages health practitioners to engage with carers in collecting non-clinical information that will personalise care. The information collected is then made available to every member of the care team, improving communication and encouraging a more person-centred approach to care.

*Ensure that Beryl's small handbag is on her bed in sight at all times. If she cannot see it she will hunt for it under the bed and has fallen like this in the past.*

TOP5 case study, 2014

#### Who's involved?

NSW Health is leading this project, with support from the Department of Family and Community Services.



## 4.2 Partners in care – community service delivery

Carers will be supported to make the most of new opportunities for themselves and their families offered by the National Disability Insurance Scheme, person centred approaches and individualised modules of support within community service delivery in NSW. Improved engagement with carers will be supported by the inclusion of quality information about carers in training provided to, for example:

- Ability Linkers (Ability Links NSW)
- social housing staff.

### Who's involved?

Carers NSW is leading this project, with support from the Department of Family and Community Services.

## 4.3 Engaging carers in local decision making

This project will make it easier for government and other public sector agencies in NSW to engage carers in decision making processes about policy and programs that impact on them by:

- developing a framework and resource on carer engagement
- developing a data base of trained carer representatives able to participate in decisions
- ongoing training and support for carers to represent the views of carers
- refining and promoting training modules about carers for government and other public sector agencies.

### Who's involved?

The Department of Family and Community Services is leading this project in partnership with Carers NSW and NSW Health.

## 5 | Improving the evidence base

### Outcome

Carers policy and practice is informed by quality evidence

Access to a good evidence base improves carer policy and programs, but we do not always analyse and use the available data and evidence.

There is already a large amount of evidence about carers. There are a number of surveys that ask carers about their needs or measure the social and economic position of carers. Some service systems have carer fields within their minimum data sets that allow them to report on the services carers use and, in some cases, what results those services have. There have been many evaluations of programs and projects that provide information about good practice when working with carers.

However, the available evidence about carers has not been brought together to inform the long term development of policy and programs.

Greater effort to bring together evidence on carer needs would improve understanding about long term trends for carers and the particular circumstances of specific groups. Better analysis of existing minimum data sets may reveal new opportunities to integrate support for carers in programs and services. Improved mechanisms to share evaluations of carer initiatives would help translate findings into practice.

Better analysis of the evidence can inform a data development agenda. This may include greater identification of carers in key data collections or priority research questions.

For the next five years, the reform direction will be on better use of the available data and research to create evidence that will shape policy and programs.

The first commitment to progress this work is:

#### 5.1 Using the evidence about carers

A working party will be formed to bring together available evidence about the focus areas and reform directions identified in this strategy. The working party will identify what evidence is possible, the extent to which the total body of evidence is able to inform policy and practice, and whether simple enhancements can be made to improve the total evidence base. The group will also explore strategies to better present, promote and disseminate evidence so that it is more accessible to policy makers and service providers.

#### Who's involved?

The Department of Family and Community Services will lead this project and include academic, government and sector partners.

# Governance and reporting framework

## Governance

The Minister for Ageing and Disability Services has responsibility for carer policy in NSW. The implementation of the NSW Carers Strategy will be led by the Department of Family and Community Services (FACS) with clear accountability to the Minister. FACS will convene a Carers Strategy Implementation Committee (CSIC) with members drawn from carer representatives, relevant government departments and external stakeholders. The CSIC will be responsible for overseeing the implementation of the strategy, including both specific projects and long term reform directions. This is intended to embed collaboration into the implementation process.

The CSIC will be chaired by FACS, meet at least twice a year and will report to the Social Policy Senior Officers Group.

The NSW Carers Advisory Council will play an independent monitoring role on the implementation of the strategy. The Council will be consulted regularly and provided with progress reports. The Council is able to provide independent advice to the Minister including on the implementation of the strategy.

## Implementation plan

A detailed implementation plan will be developed that includes clear milestones and accountabilities.

The implementation plan will be a living document. It is expected that the plan will be reviewed annually. To progress the reform directions articulated in the strategy, follow-up and additional or revised projects will be developed over the course of the strategy. FACS will update the implementation plan as projects are progressed, completed and evaluated, and as new activities are added.

## Monitoring and evaluation

A monitoring and evaluation plan will be developed to track progress against the implementation plan and each specific project, and against the higher level outcome and reform directions articulated in the strategy.

Partners with lead responsibilities under the strategy will be responsible for providing an annual progress report to the FACS.

The monitoring and evaluation plan will be overseen by the CSIC and NSW Carers Advisory Council.

FACS will compile an Annual Progress Report for the Social Policy Senior Officers Group, documenting the progress made under the implementation plan and any new projects or changes.

## Acknowledgements

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