



Mid-age carers and social inclusion: Feedback report

Never Stand Still

Arts & Social Sciences

Social Policy Research Centre



December 2016

Cathy Thomson, Trish Hill

SPRC
Social Policy Research Centre

Acknowledgements

The researchers would like to acknowledge and thank the carers and service providers who generously gave their time to meet with us and share their experiences and ideas. We would also like to thank the service providers and our partner organisations who assisted with recruitment of carers and organisation of the focus groups.

This research was supported under the Australian Research Council's Linkage Projects funding scheme (LP110400160). The study and its research methods were approved by the Human Research Ethics Committee at UNSW Australia (reference number HC11455).

The research team would like to thank the research partners who have contributed to this research project:

- University of Leeds
- Carers Australia
- The Department of Education, Employment and Workplace Relations
- NSW Health
- NSW Department of Family & Community Services
- SA Department for Communities and Social Inclusion.

Disclaimers

The views expressed herein are those of the authors, based on the discussions with carers who participated in the focus groups, and not necessarily the views of the Australian Research Council or the above departments or the responsible Ministers.

How can I find out more about the research?

Contact **Cathy Thomson** from the Social Policy Research Centre on

02 9385 7827 or **CM.Thomson@unsw.edu.au**

You are welcome to distribute this report to other people.



Why did we do this research?

Carers provide vital support that helps people with disability, long-term illness and those who are older to remain at home. Carers contribute economically and socially to Australian society. However, caring can affect the way people participate in other activities, such as employment, education and training, leisure and social life with friends and family. Providing care as well as participating in other aspects of life can also lead to poor health and low income over the short and long-term.

Social inclusion refers to people having the resources (income, health, education, information and social networks) skills and opportunities they need to participate in different aspects of life, in the way that they want to, similar to others in the community.

The project looked at carers and social inclusion and the best ways to support carers so that they can participate fully in society.

We asked carers what social inclusion means for them:

What activities carers do and what they miss out on?

What helps carers to take part in different activities and what makes it difficult?

What we should measure to see if carers were socially included?

What policy makers should do to support carers' social inclusion?

What did we do?

- Reviewed existing literature about carers and social inclusion and current ways to measure carers' social inclusion.
- Talked to service providers and carers of different ages in South Australia and New South Wales in both metropolitan and non-metropolitan locations.
- Based on the literature and what carers said, we developed some ideas about possible new indicators

What is in this report?

This report summarises mid-age carers' (aged between 26 and 64 years) experiences of social inclusion, suggestions about how to improve support for them and potential ways to measure social inclusion.

Who did the research?

The Social Policy Research Centre, UNSW is leading this Linkage Project which is funded by the Australian Research Council. The project is in partnership with Australian, NSW and South Australian government departments, the peak national Carers Association and the University of Leeds (UK).



What mid-age carers told us:

“ We want them to be as independent as possible and every day of that 18 years that I’ve spent with my son has been towards that. That’s what we are working towards. It might not be the same as an 18 year old who was in his class last year but he will eventually be able to do all these things but unless there’s supports are underneath him he just won’t.” *(Parent caring for child with autism)*

Caring situation

- Some carers’ entry into caring was via a dramatic event whereas for others it was after the birth of a child or due to a slow deterioration of the health of their relative.

“ You’ve just kind of stepped into this role whereas we’ve gradually been weaned all the way because our children were born with it. ” *(Parent caring for child with physical disability)*

- Mid-age carers provided physical, emotional and organisational support to children, siblings, spouses, parents and grandparents in addition to caring for other family members without disabilities.

“ I have two children. My eldest ... has autism. My daughter is no extra care than a 15 year old normally does, but I am also undertaking full time care of my grandmother who is at the end stage of her life. I care for my husband who had a stroke ... so he has physical and cognitive issues. ” *(Parent caring for child with autism)*

Recognition as a carer

- Many carers only realised they were a 'carer' after numerous years of providing support once they entered the service system.

For others, recognition as a carer occurred after their child, spouse or partner received a confirmed diagnosis of their condition.

“It was the nurse and after numerous admissions...I think when my son...was diagnosed at 20 months with cerebral palsy and that's when I realised my whole life had changed.” *(Parent caring for child with physical disability)*

- Even though carers provided help to their relatives out of love, they wanted recognition and acknowledgement that the support provided equated to cost savings for the government.

“Because you think if we weren't caring for the people in our lives, you just think how much would that cost the government? We do it because we love them obviously, but it would be good to get some sort of recognition.” *(Parent caring for child with physical disability)*

- Some service providers and health professionals did not take account of the carers' knowledge.

“Another area of concern, is the recognition of carers ...For me, I have been a participant and observer in my mother's life for 40 odd years, and am well aware of her difficulties...I should be regarded as a valuable asset in managing my mother's health...I had a doctor in a hospital tell me I was banned from the hospital, when all I was doing was advocating for my mother.” *(Carer of parent with physical disability)*

“We know what they need, we can list them and instead of all this other circus and taking the person to however many different people so that they can tick whatever boxes or not.” *(Parent caring for child with autism)*

Choice about taking on a caring role

- Carers have a sense of responsibility and loyalty to their relatives which is encompassed by love.

“For me, I think when your children are your children, that's what you're supposed to do.” *(Parent caring for a child with autism)*

“Well for me it was a matter of either being my husband's carer or putting him in a nursing home and that wasn't an option I wanted to do...I'm a mum, too, so I had to think about how that would impact on our daughter. I didn't do it without the thoughts that I'm going to give it a go but if it doesn't work I have to make choices.” *(Carer of spouse with physical and intellectual disability)*

What other activities are mid-age carers able to do?

Carers were involved in a variety of activities apart from caring including: paid work, education, social activities and volunteering.

“ I focus on helping other people. I work a lot, I really love it. I love running my own program ... I love being around so many autistic kids and seeing the different variation in them. I like to see [their] progress.” *(Parent caring for children with autism)*

However, carers' other activities were often restricted by their caring role.

“ I do distance education because I just cannot do it on campus anymore because [of] my husband...I suppose I'd maybe be able to now, but even when he is at supported employment I'll get a phone call from him at least once a day ... even though they are supposed to be supporting him.” *(Carer of spouse with cognitive disability)*

Many carers felt guilty about doing things for themselves, although they realised that outside activities were important so as not to burn out.

“ For me for the first 10, 12 years, all I was, was the mum, the carer and I was starting to burn out. So I actually walked past this shop and I went, “Oh, I'll go in and have a look”, and I've been now for five years quilting...I go to a couple of classes, because that's the only way outside being a carer that I actually socialise with other people.” *(Parent of child with physical disability)*





What helps mid-age carers to participate?

Public awareness

Public awareness of disability and caring facilitated carers' and their relatives' social inclusion and enhanced their sense of belonging to a community. One father and his child had recently joined a local group. The group had accepted them both without judgement. The father felt empowered by this positive experience.

“We're being included and that's a really good empowering feeling; you feel normal again. It was really encouraging.” *(Parent caring for child with autism)*

Services

Access to information about services was another key factor in assisting carers to participate. Centralised information provided carers with a gateway to services. High quality and flexible services that catered for individual needs were essential for the economic and social participation of carers and their relatives, as were professionally qualified paid workers.

“We are under NDIS. I get great support from carers, as in paid carers, to come and help... I've gone back one day a week to work in the last six months.” *(Carer of spouse with physical and intellectual disability)*

Most carers whose relatives were eligible for the NDIS had a positive experience with the process of accessing services and the level of support provided.

Carers spoke about developing 'service literacy' which involved gaining an understanding of the eligibility criteria to access support. Information was gained through asking the 'right' questions. Also carers found accessing support was often more successful if forms were completed in a way that portrayed the true extent of their relatives' needs, that is, if they were not available to assist them.

“Because my husband has various health professionals, they always say, “You have to think about what he is like on his worst day and that's what you have to tell them.” And I think it is hard because when you see him, you will not think he has a disability because he can present himself quite well.” *(Carer of spouse with cognitive disability)*

Personal time and recreation activities

Time away from their caring role in the form of retreats or respite services facilitated carers' social connections to other carers, gave them access to essential information and time for themselves.

In addition access to a Companion card helped carers and their relatives to be involved in recreational activities. It encouraged them to attend sporting events or concerts together because of the reduced costs. This was especially important for those on limited income.

Employment

Flexible employment conditions, such as working part-time, and understanding and supportive management assisted carers to maintain employment. Working gave carers a sense of satisfaction and a break from their caring role.

“ I started going back to work late last year just on weekends because my husband doesn't work on weekends unless he is away so I manage to just work once or twice ... even though it is work, but it is my own time. It is really good. ” (Parent caring for child with physical disability)





What makes it difficult for mid-age carers to participate?

Services

- Many carers lacked awareness of services and struggled for years without help. Often carers reached a crisis before accessing services.

“I don't use any services at all...I sort of tend to do a lot of things on my own now and I think there's probably a lot of carers that are the same, and I think from when I was in high school ... and there was nothing. I was never asked 'how was I?', if I needed any help or anything.” *(Carer of parent with physical disability)*

- The complex and bureaucratic systems of support often made it difficult for carers to access services. Carers felt that they had to 'jump through hoops' to receive help. They often found the questions on assessment forms unclear and seemed designed to prevent them from getting the support. They noted that questions on the forms were framed around the level of need of their relatives on their 'best day'. The carers felt that if they answered the questions based on their relatives' best day they would not get the help they needed.

“It just seems to be this game where you have to go and basically beg or work around and figure and mess with your head until you can work the system. They think for them to throw you a crumb you're just going to be grateful.” *(Parent caring for child with autism)*

- Service characteristics, such as a lack of availability, long waiting lists, restrictive respite hours and a lack of high quality respite (planned and emergency) services inhibited carers' participation. Area disadvantage also impacted on the availability and quality of services and access to transport. Previous access to respite for carers in their own right was not available under the NDIS. Carers could now only indirectly access respite through the provision of specific support services to the person needing support for example physical therapy or social activities.

“Well he wasn't getting anything before the NDIS. He was on a waiting list for some program, but the waiting list was just really long...With the NDIS, we only got very limited hours of support for him and we are struggling with that.” *(Carer of spouse with cognitive disability)*

- Carers' participation was limited by a lack of suitably trained paid care workers. Carers found that the variable quality of some paid care workers made it difficult to feel confident that their relatives would be well cared for when they were out.

“Even when they are good one day, they are not the next and balancing all of that I have a few carers that are in their early 20s. I feel like I've got more teenagers in my house and I'm sort of cleaning up after them.” *(Carer of spouse with physical and intellectual disability)*

- Some carers found it difficult to relinquish their caring responsibilities to other people.

“So being able to have a life and feeling it’s okay to let go. You can talk about it, and you can talk about it with other people, and other people can tell you, but actually doing it and feeling comfortable to do that.” *(Carer of parent with cognitive disability)*
- Some care recipients refused services:

“They are trying to give me respite for [son] to have time for [my other son] but [he] won’t accept the respite...but when you’ve got a child that won’t accept it you can’t force them into it.” *(Parent caring for child with autism)*

Inflexible employment options

- Carers often felt disadvantaged in the labour market when competing against people without caring responsibilities for jobs. Many found it difficult to combine paid work due to the unpredictable nature of some illnesses and disabilities and a lack of respite services that cover working hours.

“Well, in terms of work, is there any full-time care available? No. That’s a measure – there is nothing I can get in my area that will give a nine to five care. I’ve got a nine pick up, but a three o’clock return.” *(Carer of parent with dementia)*
- Carers were often interrupted at work or called away to deal with a crisis and felt that this reflected poorly on them as workers. Some took positions below their level of qualifications to fit in with their caring responsibilities. Inflexible work arrangements, insecure working conditions and unsympathetic managers and co-workers made it impossible for many to remain in employment.

“I used to find a doctor’s certificate with my son’s name on it wasn’t sufficient...They wouldn’t give me my sick leave pay because my name wasn’t on the certificate...I would have a 20 year old tell me, “You do realise you are a number.” I’m like, “Seriously, I can’t come into work, my son is in hospital.” That used to make me feel so small and I was scared to ring in sick.” *(Parent caring for children with autism)*
- Carers receiving the Carers Payment commented that the limit of 25 hours per week of work (paid work, volunteer work, studying or training) including travel time to be eligible for the payment restricted their employment options. Also, it created a disincentive for carers to increase their hours of work, as they would lose their carer status.



Stress

- Many were on high alert and worried constantly about the care recipient and what needed to be done to support them. Stress resulting from the constant demands of caring meant carers found it difficult to concentrate when participating in other activities.

“Switching the brain off is the other hard one, even when you’re at work, you know, it’s like “Oh, I haven’t made that appointment”, “I haven’t been to the chemist”.”
(Carer of parent with dementia)

Lacking time for personal care/support/life of their own

- Many carers focused on supporting their relatives and helping them to be socially included at the expense of their own needs.

“You know, my social life has been taking Mum for a drive because I know that’s something she enjoys. Whereas the last time I caught up with friends, I’d have to check the calendar and it’s not just has it [social life] decreased, but how has it decreased.” (Carer of parent with dementia)

- Many carers felt that they have no life of their own.

“We drop everything else to be that carer and then how do you pick the pieces back up? I think it is like sacrificing 95 per cent of who you are in the first 10 years that I remember, and it is trying to find who you are after that.” (Parent of child with autism)

Limited income

- Limited income and the expenses associated with supporting their relatives, restricted carers’ social participation. Carers noted that the Carer Payment was less than minimum wage. Also they often had to pay for private health services because the waiting lists in the public system were too long. After paying for disability related expenses and household bills carers were left with nothing to spend on outings or other activities.

“All the expenses add up and then there’s no money left to do anything.” (Carer of spouse with cognitive disability)

Future

- Many carers had to adjust their vision of the future:

“That vision’s shattered. Yeah, you can’t reset that. I was never going to be on a disability pension or a carer’s pension or whatever, there was no way, I was going to make it work. It didn’t happen.” (Parent caring for child with physical disability)

What is the impact of caring on different parts of mid-age carers' lives?

Providing care over the life course to a child, spouse or parent affected many aspects of carers' lives; their health, their relationships, their labour force participation and their current and future economic security. These effects often built up over time.

For many carers there was a cumulative impact of caring on their health both mental and physical. Carers spoke about being stressed and exhausted from responding to the demands of their caring responsibilities while fighting the service system to access support.

“I've been only doing it 16 years...and I'm bitter and twisted now. So I'm over it and I say what I say and I don't care whether you like me or not because...I don't have the time or the energy.” *(Parent of child with physical disability)*

“I just don't want to have to fight for everything.” *(Parent of child with autism)*

Caring also placed a strain on relationships with family and friends. Carers often could not attend social events at the last minute or arrived late due to the unpredictable nature of their relatives' needs. Over time invitations to events dropped off.

Carers also found it was difficult to sustain relationships with family and friends. Carers were worn out and did not have enough time or energy to participate in social activities.

“You don't have much left...to give other people. I think it gets to such a point where you're sick of your own voice saying how difficult it's been...Things haven't changed, they haven't gotten any better, in fact they are worse and you feel like when somebody else might be complaining about something else that you would find so mundane.” *(Parent of child with autism)*

- Caring demands made it impossible to find suitable work or maintain employment due to the unpredictable or high levels of needs of their relatives. Carers who had left the workforce lost valuable skills and confidence. Carers also missed the social aspect of work in addition to the income it generated.
- The damaging effect of caring responsibilities on carers' current income and future retirement income was evident. The expenses relating to their relatives' medical appointments, medications, equipment and services restricted their ability to participate socially but also prevented them from paying for services that could improve their mental and physical health, such as counselling services and gym memberships.

“It is like you have to save up to do any social things and anything I do, all the things for my husband, because the medical stuff you can't get reimbursed so the CPAP machine, that's over \$1000 and I had to buy that, all these things, so I don't have the money to do social things even if I wanted to. That's again with the NDIS not covering all the things that should be covered for somebody.” *(Carer of spouse with cognitive disability)*

- The impact of caring extended into the future as many carers were concerned about the welfare of their relatives when they could no longer support them.

“You’ve got to think future too, it is hard for us to think future but when we are not around they are going to get thrown into something.” *(Parent caring for child with disability)*

- Despite the challenges faced by carers they found providing care a rewarding experience and made them better people. Some developed new skills and worked in areas that they would not have considered prior to taking on a caring role, established valuable friendships and developed patience and compassion and an appreciation of the diversity of life.

“It’s all subjective.. but I think I’m a better person and it’s guided me into areas that I didn’t think I’d be going, like being a support worker and I really get a lot out of it, I love working with [people with disabilities] and to me there’re a light in the world compared to everything you see on the news.” *(Parent of child with autism)*





How should we measure social inclusion for mid-age carers?

Indicators to measure social inclusion suggested by mid-age carers

Health

- Percentage of carers taking anti-depressants
- Percentage of carers suffering from mental and physical isolation
- Percentage of carers who attend to their own health needs.

Social activities

- Number of people in the carers' support network
- How often carers go out socially

Relationships

- Percentage of relationship breakdowns e.g. single parent carers

Services

- Percentage of carers who need additional respite services
- Percentage of carers who access training for carers

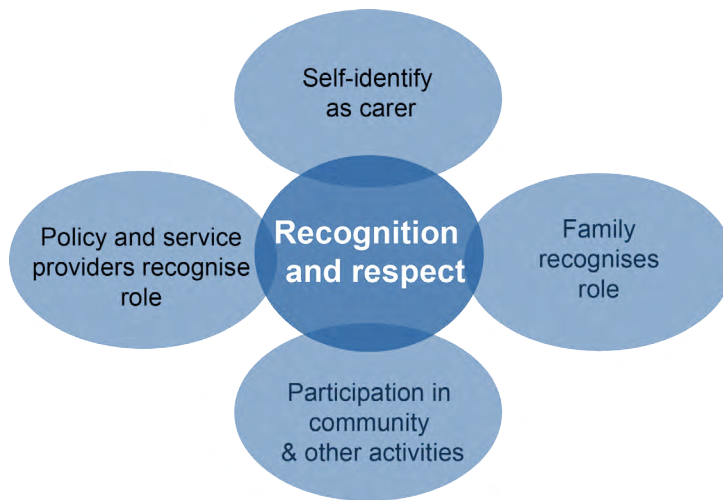
Employment

- Percentage of carers who have restricted job choice
- Percentage of carers who access training to re-enter the workforce
- Percentage of carers with access to flexible employment conditions, such as job share

Additional indicators suggested by the researchers

Below are some areas of carers' lives that we think are important to highlight that are not covered in the existing indicators of social inclusion and possible ways to measure these.

Recognition and respect



Many carers do not see themselves as carers. They view the support they provide as part of their role as a spouse, daughter/son, parent, relative or friend. This can result in carers not accessing information and services. All levels of society (carers, family, community, workplaces, services and policy makers) must recognise and respect the important role of carers in supporting the health and social care system if carers are to receive the support they need.

Examples of possible indicators of recognition and respect for the caring role include:

Carers

- Percentage of people who identify themselves as carers.
- Increases in rates of people who identify themselves as carers.

Family

- Percentage of carers who get support from family members in their caring role.
- Percentage of carers who share care responsibilities within families.

Services

- Percentage of health and community service providers who ask about carers' needs in assessments.
- Percentage of times of carers' views and knowledge are taken into account in the assessment process by service providers.

Workplaces

- Percentage of carers who feel comfortable to talk about their caring role at work.
- Percentage of workplaces that have policies to support carers.

Quality of participation



Most of the current indicators of social inclusion do not look at whether being involved in an activity is good or bad for someone. For example, carers may have a job but do not have enough time to take part in other activities. This can also have an impact on their relationships with family and friends and also the people they support.

Examples of possible indicators include:

Relationships

- Impact of caring role on relationships with family and friends.

Social support and isolation

- Percentage of carers who can get help from someone when needed.
- Frequency of carers getting together socially with friends or family members not living with them.

Time pressure

- Percentage of carers who always or often feel rushed or pressed for time.

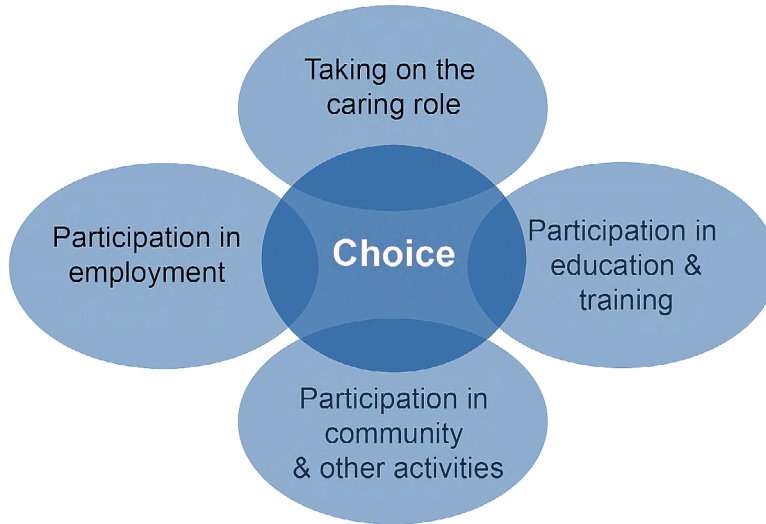
Employment

- Carers' satisfaction with work-family balance.
- Carers' access to flexible work arrangements: work from home, flexible start and finish times, carers leave, part-time work.

Caring situation

- Percentage of carers with unmet need for services.
- Percentage of carers with access to information and training about their caring role.

Opportunities for choice

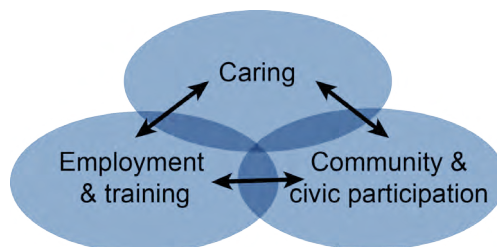


Some carers take on the caring role because there is no other alternative. This lack of choice can have negative impacts on other parts of life, such as entering or keeping a job, education and training, community involvement or spending time with friends.

Examples of possible indicators include:

- Percentage of carers who took on the caring role because there were no alternative arrangements available.
- Percentage of carers who have choices about the services they can access to support their caring role.
- Percentage of carers who changed jobs since taking on the caring role.
- Percentage of people who would like to be employed while caring but cannot due to a lack of alternative arrangements.
- Percentage of carers who had to leave work due to caring or reduced the hours of their employment.
- Percentage of carers who cannot participate in social or community activities due to caring.

Spillover effects



Many carers have a job and do other things as well as providing help and support. Participating in a number of activities can have spillover effects which can be negative or positive. For example, providing care can have a negative effect on paid work. However, being employed can provide more income and/or a break from caring.

Examples of possible indicators include:

Positive

- Percentage of carers who feel that having both work and caring responsibilities makes them a well-rounded person.
- Percentage of carers who feel that working makes them a better carer.

Negative

- Percentage of carers who worry about what goes on with the person they care for while they are at work.
- Percentage of carers who feel that because of their caring responsibilities, they have to turn down work activities or opportunities that they would prefer to take on.
- Percentage of carers who feel that working leaves them with too little time or energy to be the kind of carer they want to be.

Effects over time



Many carers move in and out of different caring roles over the years. This can have a negative effect on other aspects of life and these can build up over time. For example, some carers may have moved in and out of jobs because of different caring roles. This can have a negative impact on contributions to superannuation savings and retirement income.

Examples of possible indicators include:

- Number and length of caring roles over time
- Age at which care responsibilities commenced
- Percentage of carers who gave up work to care
- Percentage of carers who worked part-time to care
- Percentage of carers who own their own home
- Level of superannuation savings for carers.

Mid-age carers' suggestions to policy makers and service providers

Awareness

- Increase public awareness of caring roles, disability and mental illness through TV and social media.
- Better advertising and promotion of available services.
- One-stop-shop for information about available support and/or a 'show bag' of information for carers
- Training for health care professional about disability and the important role of the carer.
- Organise a facilitated forum where carers tell their stories to politicians and health.

Access to services

- Availability and access to training for carers, such as how to deal with the stress associated with caring, lifting and handling techniques.
- Increased support for GPs to be a key access point to services.
- Access to counselling or support workers to assist with the stress associated with caring and other mental health issues.
- Programs to help carers have the opportunity for exercise, such as gym membership.
- Greater access to services that target different needs ie different types of support groups, appropriate services for the care recipient encompassing things that they like and enjoy.
- Increase access to culturally appropriate services.
- Although the relatives of some carers are better off under the NDIS they still need increased access to high quality respite services (planned and emergency).

Paid care staff

- Some paid carers were not well paid and lacked experience to care for people with certain disabilities.
- Increased training and improved conditions for paid workers.

Employment

- Increased access to flexible employment conditions, such as job share.
- A carers subsidy for employers as an incentive to employ carers, particularly those who had been out of the workforce and lacked the necessary skills to re-enter the workforce.
- Increase the cap on the number of hours carers are allowed to work while receiving the Carers Payment.
- Allow carers on the Carers Payment to access support through employment agencies and training courses similar to recipients of the New Start Allowance.
- Availability and access to workplace training for carers re-entering the workforce.

What will happen with this research now?

We will bring together the different parts of the research into a report for policy makers and service providers about how to improve YACs' social inclusion:

- literature review
- data and policy analysis
- focus groups with carers.

To find out more about our research, contact:

Cathy Thomson

Research Fellow

Social Policy Research Centre

T 02 9385 7827

E CM.Thomson@unsw.edu.au

or visit:

www.sprc.unsw.edu.au/research/projects/carers-and-social-inclusion/

© UNSW Australia 2015

Social Policy Research Centre

UNSW Arts & Social Sciences
UNSW Australia
UNSW Sydney NSW 2052 Australia

T +61 2 9385 7800

F +61 2 9385 7838

E sprc@unsw.edu.au

W www.sprc.unsw.edu.au