



Older carers and social inclusion: Feedback report

Never Stand Still

Arts & Social Sciences

Social Policy Research Centre



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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

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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 older carers' (aged 65 years and older) 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 older carers told us:

“Can I just say because I have come from a point where I was the sole carer and doing everything and brought [daughter] up to a position where she can now be a contribution rather than a drain on society, yes I can do more now that she has got some help. I have broken my hip twice so therefore I can't go out and just do a manual job or whatever like that, but that doesn't mean to say I don't want to be a contribution and there's the area of volunteer which I would like to do more in as it progresses and so on, but we are tired, we are exhausted and we are not given credit for that.”

Caring situation

The caring situations of older carers varied, however, most had provided support to their spouse, parent or child for many years. Many carers had multiple caring responsibilities over time which entailed caring at both ends of life.

“I have a daughter who has got Asperger's Syndrome. I cared for her on my own until two and a half years ago...and the last 10, 15 years I have also been caring for my parents. Dad is no longer alive, he had Parkinson's with the dementia at the end. It is now two years since he has died, and mum's now got.”

“I care for two little grandchildren who have been placed in my care through the Children's Court, and the biological mother is my youngest daughter...I have been caring for them for four years.”

Other older carers had simultaneous caring responsibilities for example a spouse and an ageing parent or a child and grandchild.

“My daughter...has got a genetic disease... It has been full on care for her all of her life. She lives in a house but I go down to her place practically every day. She did get married...and she had a little boy that has got exactly the same disease... He lives with me.”

“Five years ago I was looking after my mother, she was living alongside of us on our property, and she got cancer and so for two years I cared for her until she passed away. And at the same time my wife was developing dementia...for the last three years more or less a full time job looking after her.”

Some had cared for extensive periods of time before they found out about services or income support for carers.

“It was when the district nurse was coming in to dress my husband’s ulcers, he said to my husband, “Who mows the lawn?” “My wife.” “Who does your shopping?” “The wife.” “Who does this?” “The wife.” And he said to me, “Do you get carers?” I said, “What’s that?” And he said, “Get the paper, I will sign it for you.” I knew nothing about it until then and by that time grandson was about 10, so I had nothing for daughter [now aged over 40 years].”

Another couple with a child with disability had cared for over 50 years without help.

“So we’ve been looking after him for 59 years and it was probably not up until three years ago that our solicitor friend said that we should put in for being a carer because as we are getting older we don’t know what’s going to happen to him when we are not around, so I applied to be his carer and so he lives with us.”

Some carers felt that they were wearing multiple ‘hats’ and oscillated between being a carer and a partner, parent or grandparent and missed their previous relationships.

“Well I had the feeling of guilt because within myself I thought, you know, I’m finding it so hard to be a husband and a carer... And what I find is that if my wife goes into respite, I actually immediately sort of switch to the husband role because I’m missing her, and I suddenly get refreshed and I think “God, I still do feel like a husband”, and then as soon as she comes home, that one gets switched back...this process is a rollercoaster.”

Reciprocal caring roles:

“Sometimes I’m the carer and sometimes he’s the carer if I’ve had surgery. It’s sort of - because you’re both together it’s - the role changes at times. So you just sort of do it.”

Recognition as a carer

Carers felt that there was a lack of understanding of the caring role and a need for increased public awareness of their contribution.

“And we are doing this for nothing and we are not getting any recognition for it either.”

Many carers were unaware that they were carers until they stopped working and applied for income support.

“I called myself a carer when I stopped work and I signed a form; what was my occupation because I was a wife. Some carers came in; they were carers. I was a wife. I did, you know, 99 per cent of the caring. So the form - and government forms...What is your position? Oh, I'm a carer. So that's when I realised that I'm actually a carer. But to me I'm a wife.”

Carers felt that their needs were not taken into account.

“But then no one ever comes to you and thinks to say, “Well, are you coping with life?” Which, let's face it, it's damned hard, isn't it, you know...And you've all this responsibility after, but nobody - granted we know the person who's affected, they should have the most care obviously. We're just burden - the by-product of it; the carers. But there is room for people to help the carers - if it's only talking to them.”

Carers were often unaware of the supports available to them before they identified as a carer.

“It almost comes accidentally that you're a carer I don't think you're very aware of what facilities are available for you. I think I was probably more aware of it because when I gave up work, because I had to, and my wife was sort of caring for me then for a fair while...when I got better she got worse so I sort of just took over that role.”

Love

Despite providing support to their child, parent or spouse being difficult carers did not view it as a burden.

“I get so much love, I don't feel that it is a chore.”

Choice about taking on caring

Caring was viewed as a normal part of a relationship.

“Well, my son was sick from birth so I was always caring for him as a child.”

Some carers were reluctant to accept the label of carer.

“I think carer is just a word, you know. I still accept it's just a word because obviously when you've been married for many years, as long as I have, you know, it's the normal thing to look after your wife or your wife would look after me.”

What other activities are older carers able to do?

Activities other than providing support that carers were involved in included: paid work, social activities and volunteering. However, many of these activities were fitted in around their caring responsibilities.

“I do voluntary work one day a week. I’m sort of very conscious of making sure that I’m not just sort of stuck at home.”

“I go to craft and I don’t have very much time at home because I have to visit [daughter] to make sure that she is okay and keep her on level because if things go wrong and upset her she is likely to self-harm and you just can’t relax.”

The support provided by carers helped their relative negotiate and understand the world. In some cases they helped them to maintain relationships with others and assisted them to be socially included. Carers drove their relative to social activities and or/and encouraged them to participate in different activities. For example a mother encouraged/cajoled her child with a disability to go to supported employment.

“Because he missed out on post school options because he was that little bit older and he worked a couple of days in supported employment...Now it’s because he works...five days a week. I said, Yes, because I make him go...It’s the only interaction he has with people. Unfortunately that’s the way it is.”

Many carers took on additional roles that the care recipient used to have responsibility for.

“I had to work out how to be a mechanic. I mean, I had some basic knowledge because I’ve come off a farm and I’m really glad because I’ve got good grandsons now who can take over all that. I’m always having to shift or change something on a wheelchair.”



What helps older carers to participate?

Services

Access to respite services assisted carers to participate in other activities.

“I have a carer come in two hours a week every week, and in those two hours I did my shopping one week and another week I did a little bit of volunteering work at a bookshop.”

Carer support services organised outings and retreats for carers and their relatives that enabled them to enjoy social activities.

“For me...not having to think of what we can do, or plan things. I mean, you've got so much going on in your head – you're doing the finances, the house, the driving – and it's just nice to sit back and someone else do it for you.”

- Some families had accessed services through the NDIS and generally they were satisfied with the level of support they received.
- Access to flexible and high quality respite also enabled their relatives to be included in other activities.

“Well I do it but he goes out five days a week to [name of service] and he absolutely loves that and they do all sorts of things with him.”

Support network

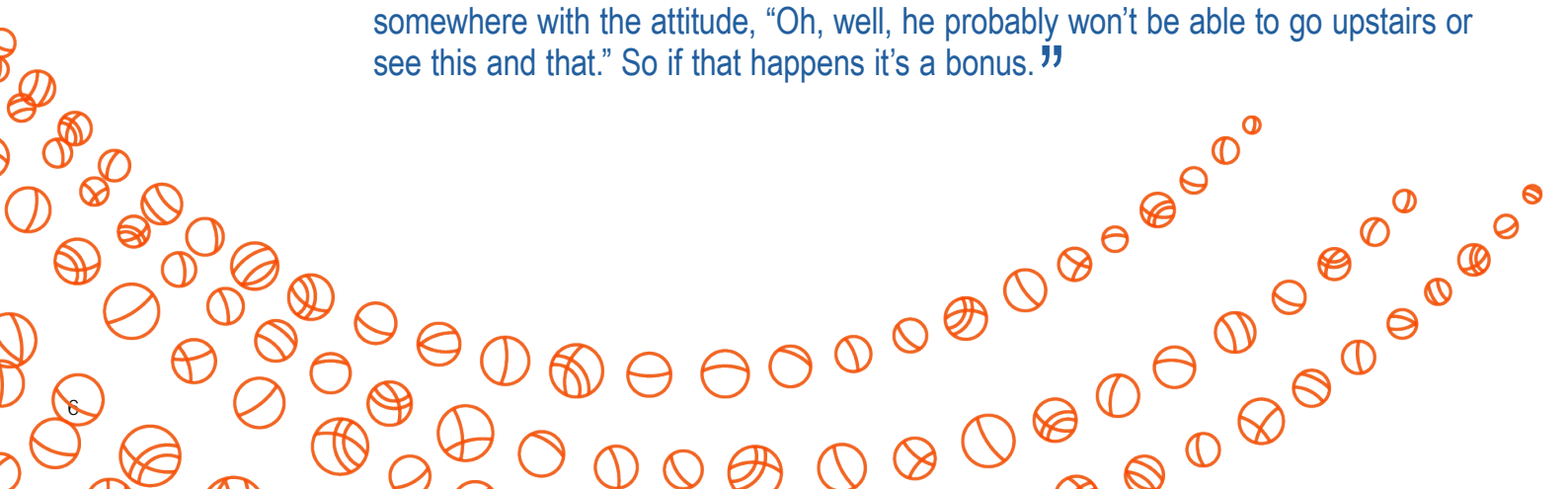
Access to a support network, for example living in a retirement village with access to a well-developed support network in addition to family support assisted carers to continue in their caring role.

“When I had my second hip replacement done my daughter flew over with her husband to look after me and look after my son.”

Accessibility

Accessibility in public spaces is vital for carers and their relatives to enjoy outings.

“It's surprising, some of the places like that; the art gallery and the museums and different places around Australia, have got those lifters now...you have to go somewhere with the attitude, “Oh, well, he probably won't be able to go upstairs or see this and that.” So if that happens it's a bonus.”





What makes it difficult for older carers to participate?

Health

Many carers suffered from mental and physical exhaustion and ignored their own health needs:

“I think a lot of the things that you have to give up, I used to be a volunteer, just make cups of tea and that sort of thing, and I loved it. I used to play sport of some sort, did a lot of quilting but I got to that stage that I couldn't concentrate on it anymore. My blood pressure went up. I had side effects from so many medications but I wasn't well for 12 months about the same time as [husband] was at his worst, too.”

Time pressure

Many carers could not switch off, even when having a break due to being on 'alert 24 hours a day'.

“It is a colossal amount of work and it is not a 9 to 5 thing.”

You can't switch off.

Carers often felt rushed and pressed for time.

“Well, I didn't go out otherwise, but even just the shopping, I would just rush up the street and back home again...I used to just grab what I wanted, and it was always just rush, rush, the whole time. No, we didn't go out.”

Behavioural changes

“The hardest part to deal with is the behavioural part, that's it. I can deal with home and running all that and the garden and doing the papers I've learnt to do, but it's the behavioural thing that really upsets me that how to deal with it.”

Access issues

Access issues for people with disabilities for example toilets and holiday accommodation:

“There was a disabled toilet; a big toilet, it was fantastic. Get the wheelchair in there, can't close the door. The door goes this way. There was a car park behind it, he's leaning forward doing a wee in full view of everybody.”

Services

A number of service characteristics made it difficult for carers to access adequate and appropriate support. Many experienced a lack of information about services and felt that the existing government websites were not user-friendly for older people.

- Ad hoc entry into the services system often after a crisis:

“But you just keep going and going until I became ill. You might look at me and think, “Oh, she looks all right,” you know. But underneath...”
- A lack of information about services and income support:

“And a lot of things that he was entitled to we didn’t know about.”
- Adequacy of services:

“But I find it difficult to get respite in as much as I go to golf, well I need a carer to look after him which they don’t – you know, mostly they do it now – but I need that time just away to, I mean I do a bit more, but I just feel I need that time away just to refresh my batteries.”
- Other service characteristics restricted carers’ participation were inadequate support services, especially for young people with high needs, particularly in non-metropolitan areas. The lack of appropriate and safe respite care options made it difficult to leave the care recipient because they could not be confident that they would well cared for and safe.
- Lack of appropriately trained workers in residential care and hospitals:

“Yeah, they have to feel comfortable with someone.”

“The same as respite. She didn’t want me to have respite. Right. Because it was for me and not for her and she had the uncomfortable feeling. She couldn’t even push a button in the hospital for emergency for a nurse. She couldn’t change TV channels, couldn’t do anything else.”
- Transport in rural areas.
- Inability to plan ahead and inflexible service delivery.

Eligibility

Transition periods for younger people with disabilities as care recipients moved from one age bracket to the next and the eligibility requirements for entry into the NDIS.

- “Well, because he’s moved up - yes, he’s sort of, yeah, the goal posts have moved each time, which is a bit frustrating. So then you start the whole role again and you think - it’s a little bit daunting when you think, well, my God, you know, another 20 years, I hope to God I live that long. So my daughter can have a life with her husband before she has to take over the role of caring. It makes it a bit hard.”

Income

Providing support often put a strain on carers' finances.

“ My daughter is fiercely independent. She is determined to make her own way – and my finances have been not great, but been really, really drained, not that I ever put any pressure on her. I did without myself, as you would do to help your child, until she eventually went to Centrelink. ”

Employment

Some carers in the focus groups had juggled both caring responsibilities and paid work for many years. However, as care needs increased or changed it often became impossible for them to continue working.

“ There's no way we can work, we can't. ”

“ But having to leave work, even though I was eligible to retire, I would have liked to have stayed working, but I needed to leave to cope - to look after him and to be there for him because of the mental health issues that arise with intellectual disability. ”



What is the impact of caring on different parts of older carers' lives?

- Carers experienced strains on their relationships with other family members and friends.

“ I just find now it would be lovely to go and see another - an older sister that's in the country, like, to do these other things, which you just can't do. You're very restricted and you just sort of accept it. I mean, I'd like to probably - we're hoping, we're planning, you know, to go over to see my daughter, say, next year. But I'd have to take six months preparing and hope I can get him to walk out the damn door with me, because we've had that before where he wouldn't walk out the door when the taxi's arrived. So all these issues and it gets very frustrating. ”

- Some carers had relocated to provide support to their relatives and this had led them to disconnect from their social networks.

“ I thought right, I have got to do this, I don't know how I will do it but I will do it. I have osteoarthritis in my hands and in my feet but nonetheless I meet a challenge and I did it. I got myself busy, got the properties sold, got packing done with a lot of help from wonderful friends, and I moved. ”

- Some carers had lost contact with their friends due to the stigma associated with particular conditions.

“ We're actually living or sort of – not living, but you're managing two lives, and so you're not only thinking about yourself, but you've got to actually think about the other person, what's she doing, is that okay? It's like having a child but with an adult mind, especially when you go out. You know, you might say well we can go out together, but that's as much stress, if not more. ”

- Many carers felt that they lived in a constricted world.

“ Yeah, you just feel as though your whole life has sort of shrunk – you know, just shrunk – it's not your life any more because you're caring for someone. ”

- Often carers' social life was restricted.

“ So, I mean, you know, for me it was problematic getting my husband to the shops and then getting around the shops because of...obstacles in the way...I solved that problem by never going to the shops. I started ordering my groceries online and had them delivered at home, which meant that I wasn't getting out to do that and socialising. ”

“ Other than pay bills and do the shopping, that's about the total. ”

“ Yeah, you just don't have any [social life]. ”

- Carers experienced grief associated with changes in their relationships.

“I think some of the stress around that too, is that grief around the change of relationships too, that you’ve actually gone from being a partner or a daughter or a whatever, to simply having to be the parent, you know, regardless of the what the person’s situation is.”

- Caring responsibilities had a cumulative impact on the health (mental and physical) of the carers.

“It’s aging me and I’m thinking, another 10 years, what’s going to happen? I’m worrying about - I don’t want to become withdrawn. I want to still be a person. I was used to being in - I am an intelligent person and working in, you know, productive work.”

“Well at the moment, going into the aged care units it is a bit of a shock to the system and we’ve done voluntary work right up until the last six months, and all I want to do now is relax for six months. There is nothing important that I want to do, just sit back and we’ve been offered to help in the village but I said no, just give me another six months, I just want to relax because we’ve worked hard and we are still working.”

- Many carers were concerned about their current and future financial security.

“I have such reduced finances to help her [daughter] and I had a stroke three months ago, I guess from the stress of it all, plus the stress of moving was enormous and I don’t have my friends around me. I mean we are in email contact and on the phone and so forth so I’m trying to make some friends and so forth.”

Holidays

- Many could not enjoy holidays due to poor disability access and high costs.

“What we’re finding is when we - well, we don’t go much - we don’t go many places now, although we was away the week before last for five days. But the general public either doesn’t want to know about disabilities or doesn’t realise what it’s all about. We had - all our motels, just four nights; we told the travel agent we need disability access and walk in shower and all these sorts of things.”

Future concerns

- Carers were concerned about how they would afford to pay for their future care needs, as well as the needs of themselves and their relatives. Older parents of adult children with disabilities were apprehensive about the future and who would support for their children if they were hospitalised or when they could no longer provide care. Ideally parents wanted access to a range of high quality group homes or supported accommodation for their children.

“It worries you...I suppose for 38 years I've looked after him...I'm hoping I can live another 20...I did ask about accommodation because it would be lovely if you had a cottage with his peers...and then still come home and spend some time with me at the weekend. But there's nothing. I was told if anything happened, if it was a crisis, they would find something. Well, by then the shock of losing mum would be horrendous.”

- Despite the difficulties carers talked about learning a lot through their caring role, especially how not to be selfish. Providing support to their relatives gave them a different perspective on life. For one carer, who supported her grandson with disabilities, caring responsibilities helped her through the grieving process after her husband's death.

“As hard as it is I wouldn't change a thing...it puts you in a different light, you've got to think of somebody else.”

How should we measure social inclusion for older carers?

Indicators to measure social inclusion suggested by older carers

Health

- Rating of carers' health including: weight, sleep deprivation
- Changes in carers' health over time
- Ratings of mental health, depression and the number of carers taking anti-depressants
- Level of carers' stress

Isolation

- Social isolation of carers
- Access to social networks

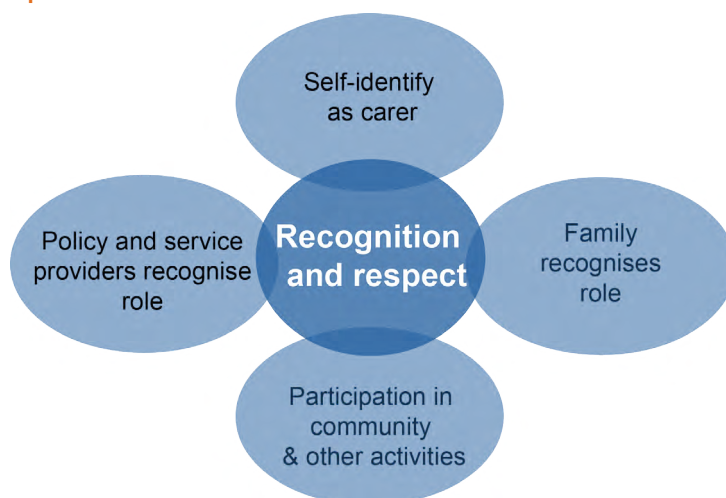
Finances

- Ratings of financial stress of carers

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

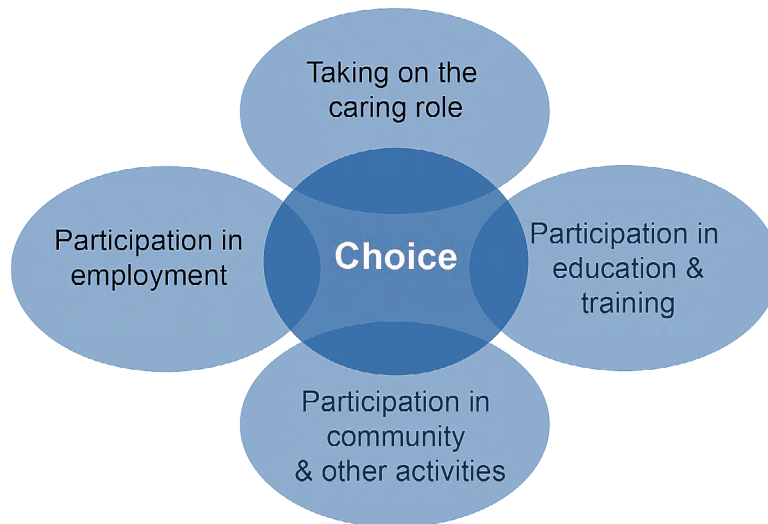
- Percentage of carers who always or often feel rushed or pressed for time.

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.

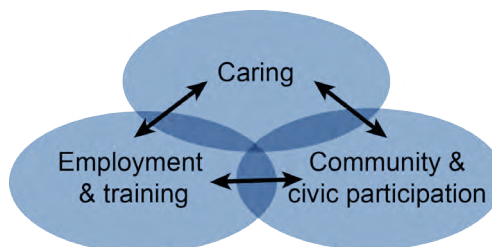


Some carers take on the caring role because there is no other alternative. This lack of choice can have negative impacts on other parts of life, such as entering or keeping a job, education and training, community involvement or spending time with friends.

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

Older carers' suggestions to policy makers and service providers

Access to information

- Access to information about services and income support for carers when the person they are caring for is discharged from hospital.
- Development of an information website that caters for the needs of older people.
- Include older people in the planning and development of the website.

Services

- Access to high quality care that was fun and engaging was viewed as essential for the social inclusion of carers and care recipients.
- Activities that carers and care recipients could attend together.
- More activities that enhance the social participation of younger people with disabilities, such as group activities.
- Increased access to group homes and supported accommodation for adult children with disabilities.
- Improved access to preventative respite and emergency respite.
- Services tailored to the individual needs of carers and people in need of support.
- More support for carers after caring ends.
- Increase CALD appropriate support for carers and their relatives.
- Address program eligibility gaps for young people with disability as they move from one age bracket for example for young people moving into the NDIS in SA.



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:

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

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