



Young adult carers and social inclusion: Feedback report

Never Stand Still

Arts & Social Sciences

Social Policy Research Centre



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Cathy Thomson, Trish Hill

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- SA Department for Communities and Social Inclusion.

Disclaimer

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 young adult carers' (aged between 18 and 25 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 young adult carers told us:

Caring situation

Young adult carers' (YACs) entry into caring roles varied. Some had grown up in a caring role whereas others had become a carer after a life event that significantly changed their family situation.

“ I’ve been caring for my mum for as long as I can remember. She suffers from a physical disability as well as a mental disability and as of recently I’ve also been caring for my grandmother who just has just been diagnosed with cancer. ”

“ Mine’s different..., my mum was sort of an instant thing. So, like, she was perfect one day and the next day she had a brain injury. ”

The support provided by YACs varied considerably. They provided physical, emotional and practical support, as well as monitoring.

Recognition as a carer

YACs only became aware that they were carers after coming in contact with services. However, when asked, most YACs were unsure how they first became involved with the services. Once in contact with services the young people were linked into other supports, such as camps, social activities, respite services and support groups.

“ Well for me I never really thought about it, you know, it was just part of the daily routine, looking after the brother and all... I didn't realise I was a carer until I started coming to [name of service]. ”

YACs wanted to be appreciated for the work they did and acknowledgment of difficulties they had to overcome to complete schooling and have a social life.

“ Acknowledgment is like the first thing, acknowledge that there are so many young carers out there, and older carers, that aren't appreciated. ”

YACs also wanted recognition of their knowledge, skills and expertise in their caring role from health professionals and other service providers.

“ A big issue I am facing right now is basically being treated as a minor instead of being treated as an adult. We care and still medical practitioners treat us like we know nothing about what's going on. ”

Choice and obligation in becoming a carer

For many YACs caring was an integral part of their daily routine within family life; they thought all young people provided care. Some were primary carers for a grandparent, parent or child, while others helped their parents care for a sibling. Other carers had entered their caring role abruptly, but still considered this to be a normal part of family life. Some YACs commented that they had little choice about taking on caring roles given complex family dynamics and other family members opting out of providing support.

“ I have older brothers... we all lived with mum, like, before everything happened. Now they're all off on their own. They don't see mum now because they don't like to see mum as the way she is... which is upsetting to me because I have to deal with it daily where they choose not to, and they choose not to support my carer role. ”

What other activities are young adult carers able to do?

Challenges of multiple activities

Generally the YACs' ability to participate in other activities, such as social activities, paid work, education and employment, was restricted by their caring responsibilities.

The young people talked about having to choose between different activities, whereas continuing to provide care was taken as a given.

“ ... I doubt whether you'll find many carers that can do more than one thing. So you choose between your education, working or a social life. ”

The degree to which caring responsibilities impacted on YACs doing other activities varied and depended on the characteristics of the YAC, the intensity of the support given and help from other family members and services.

Social Activities

Access to services provided the YACs with connections to other young carers through support groups, social activities and retreats. These activities reduced the young people's feelings of isolation by providing them with a chance to meet other young people who understood their situation, gave them a break from caring and something to look forward to.

“ I've just had so much going on in life at the moment and I'm so stressed out. You don't even know why you just feel like crying...And knowing that I've got the retreat next week... So I'm, like, “Yay, I've got something to look forward to”. I know I'm having a night out. ”

Education

Caring made it difficult for some YACs to study at TAFE or university. For a number of young people, their caring responsibilities had also made it hard to complete high school due to a lack of understanding and flexibility from the teaching staff.

“ One of my teachers pretty much told me I had to choose 'school or your family. You can't have both'. So I ended up dropping out of school. ”

Employment

Many YACs found it hard to get a job after they left school. They talked about limited job opportunities given their lack of experience and problems associated with finding work that fitted in with their caring responsibilities. Finding paid work required persistence and luck. Some opted to take whatever job was offered just to get some experience. Competition was fierce for the limited jobs. Most worked part-time and one YAC had two part-time jobs to cover expenses.

“ So I’m working full-time hours this year, two jobs, to sustain myself, and I’m studying part-time as well. I’ve found it’s pretty difficult emotionally and physically. Like today I was up at 4.30, started at 6.00 at my job at the shop to 2.30, and then 3.00 to 6.00. I usually go home after that and I’ll help cook, and I’ll help bath the little ones. ”

Only one YAC had ‘fallen’ into a part-time job when she walked past a newly established childcare centre and inquired about a position. She put it down to being in the right place at the right time.

“ They opened a new centre...and I just spoke to the receptionist there and I handed in my resume and then the next day they said, “We want you to come in for an interview.” And then the next day after that they said, “We want you to work for us.” ”

Social media

Access to social media, at this stage did not help some YACs to participate in other activities. However, it did provide them with an opportunity to assume a different persona and connect with other young people without talking about their caring experiences. Many found the postings on social media concerned trivial matters and could not relate to the discussions, given the problems they faced at home. One YAC stated:

“ The biggest problem is the people that go on there [social media] and have a massive whinge about something so minor. ”





What helps young carers to participate?

Services

- Access to flexible and supportive services, such as Carer Support Services, Raw Energy and the WAVE program. Carer support services gave YACs financial support (eg paying for gym memberships and car registration), emotional support, organised support groups, which gave them time to themselves, respite from caring and a social outlet. These types of support were vital for YACs to sustain their caring roles.

A common experience for the young adult carers was that once in contact with the carer support service system they were well supported with individualised and flexible support:

“ I think Carer Support for me, like, is more emotional support. I mean, I get a lot of financial support from them too... If I'm having a really bad day I know I can call up and talk to someone because... I don't have much family support at all... A lot of friends don't understand, especially at our age. ”

- Adequate support for the family member:

“ Well my brother he works [in supported employment] and he loves his job and he's happy and he's got lots of friends...he's happy and as long as he's happy I'm happy. ”

Education

- Flexible and supportive learning environments, such as distance learning and special consideration provisions at school and university:

“ ..when I first started caring I was in this group through my high school... called WAVE which was probably the best experience ever...They actually got me a few courses... things that I could attend. So I ended up getting my Community Service Cert II...So at the moment I'm studying my Diploma of Nursing. ”

Employment

- Flexible and supportive employment:

“ Yeah, like my job, my boss is great. I don't work past 2.30 and that allows me to work my other job, and I'm home just before dinner so I can help out with dinner, so I'm not working long nights which is good. Like, I work long hours but it's just during the day which is really good, and it's kind of fixed hours so I know that whether I'm working a six or an eight hour day, it's not going to go past 2.30. ”

Transport

- Once the young adult carers gained their licence it gave them independence but it also enabled them to expand the type of support they provided to their families. As one young adult carer explained:

“ And now we have a small car I can say “I’ll go and do the grocery shopping, don’t worry about packing all the kids in the car and putting [name] in the hoist and then trying to walk him around the shopping centre for an hour and a half pulling all the stuff off the shelves”. Yeah, it’s so much easier now driving. ”

Health

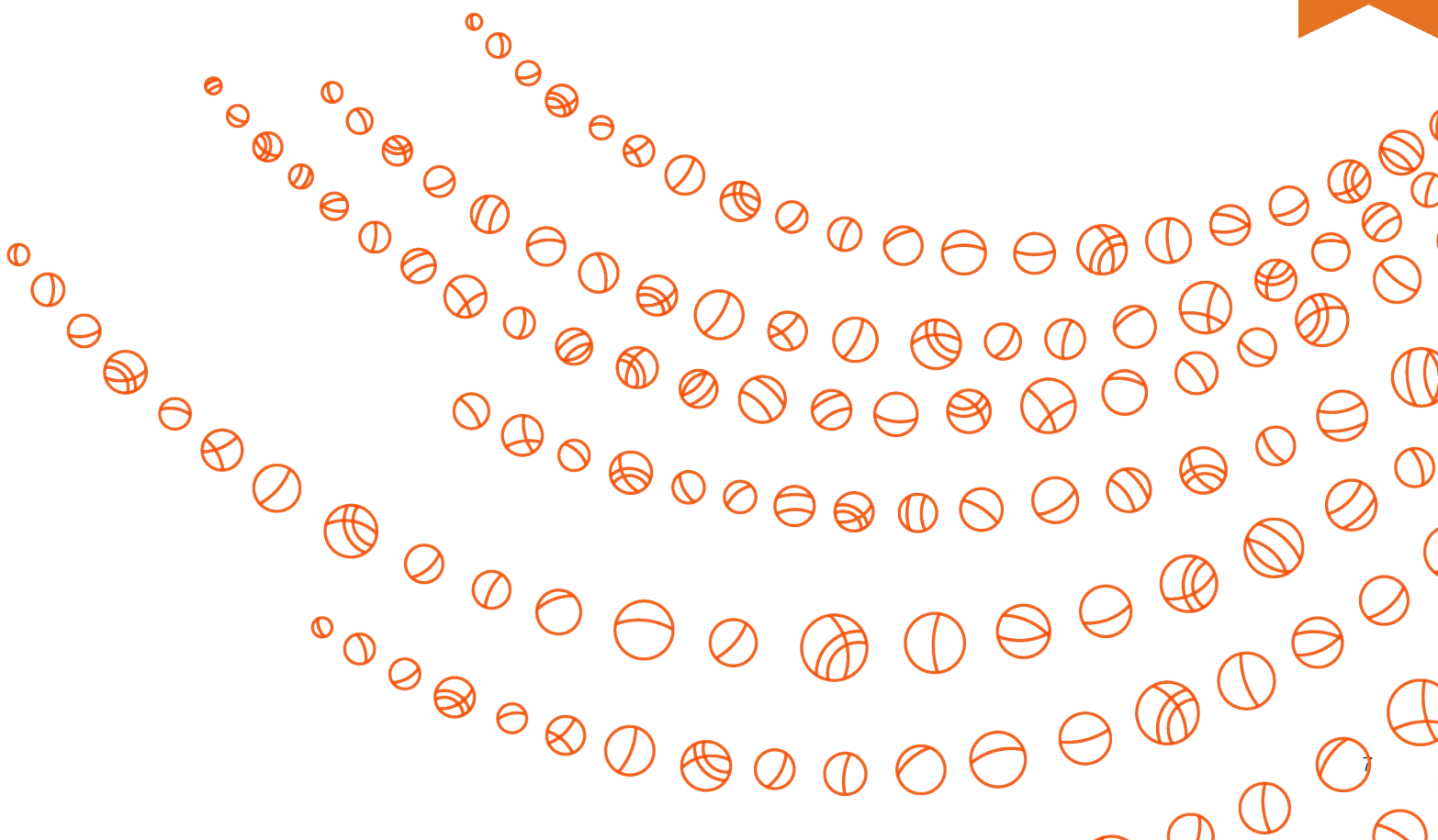
Many YACs do not have enough the time or money to attend to their health needs. Access to a gym membership through a Carer support service helped to improve YACs’ mental and physical fitness:

“ Yeah. Carer support is amazing... I can’t even explain how many breakdowns I would have had if I didn’t have this programme. They signed me up for a gym membership, so that’s making me, like, really really good and making my lifestyle healthy. It’s a 24 hour gym so I can go there any time I need to for a stress reliever. ”

Support networks

- Access to support from family and friends:

“ Just my other brothers and sisters, they were really supportive of me and my friends and people, here at Carer’s Link. ”





What makes it difficult for young carers to participate?

Services

- Lack of access to high quality, appropriate and affordable respite.
- Ad hoc entry into the services system.
- A lack of information about services.
- Lack of flexible respite services for example for to cover employed carers work hours.

A common experience for young adult carers was to stumble into services:

“ I’m not sure how but I found a programme called Raw Energy and I was joined up with that until I think 18 or 16. I can’t remember when the programme was cut off. Then I had no support at all and mum saw this programme. ”

- Geographical location determining access to services.
- Lack of experienced paid carers which make it hard for carers to feel confident that the person will be well cared for:

“ I think that the easier the life is of the person that you’re caring for, the easier the caring role is. I don’t know, but yeah, say if there was more funding or more services then it might not decrease my caring role but it would certainly increase my wellbeing. ”

Transport

- Accessing transport, compounded by difficulties learning to drive, particularly in non-metropolitan areas:

“ I have my Ls, I’ve had my Ls for over two years, just because my dad... it was just hard with him and his diabetes and just, he was always tired or something. ”

Health/ Stress/ on call 24/7

- Mental exhaustion and anxiety from constantly worrying about the person being supported. Many YACs could not switch off from their caring responsibilities:

“ I suppose, like, you’re - although you’re caring for, you know, who you’re caring for, but you’re also trying to live your life as well. So you’re doing literally 101 things at a time. So your brain’s just always on. It just keeps on going. ”

- The unpredictable episodic nature of illness:

“ At times she’d be too upset or too sick to actually be able to do anything. You know, she can’t drive, Dad would be at work so we’d miss out on seeing friends and getting to stuff sometimes. ”

Education

- Unsupportive learning environments:

“ I have a four week placement that’s supposed to start in three weeks that I am not going on because... I’m not going to have that respite...Then at the end of my year I’ve got six more weeks, like, that I have to get respite for... It’s [the placement] not flexible. But you can’t go in and say, “Well, I’ll do two weeks, two days a week for the next however long.” They don’t offer that. ”

- Costs associated with studying and lack of flexibility in study timetables:

“ If someone says, “I finished year 12,” that’s held higher than, “I finished [Year 12] while being a full time carer for my mum and doing all these other things.” So I didn’t get into TAFE straight away. I had to fight. To look for other alternatives is really stressful. I think one of them is something like \$200 a week I had to pay to study. So I couldn’t do that. The other one was certain days that I couldn’t do. ”

Employment

- Limited job opportunities, particularly in non-metropolitan areas:

“ Leaving school, trying to find a job isn’t easy...that’s how I got my job...I knew the manager... you know you get some kids who haven’t worked at all through their high school lives, you know, sorry, nothing for you because you don’t have any experience. ”

Work-life balance

- Lack of understanding and flexibility from teachers and/or employers
- Difficulties associated with balancing school/university and/or paid work and caring responsibilities:

“ I find that it’s just physically draining. Even if somebody was, like, okay, here’s someone to look after your mum, go to work. I would be, like, I can’t do it. I am that physically drained that I am not going to be able to stand there. ”

Access to holidays

- Challenges having family holidays because of care and financial issues:

“ Like, we’re all in the one car a couple of weeks ago and it was just so nice, but it was such a rare thing, I can’t remember the last time we all went on a holiday together. ”

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

Social worlds

YACs talked about the lack of spontaneity in their lives due to caring responsibilities. Most of the YACs' social life was restricted or non-existent due to friends dropping off and many of the young people found it difficult to relate to people of their age.

“ ...for a lot of us this is the majority of our social life, like, carer's support. Because not many people understand what we do, other than if you're not a carer you can never really understand a carer. ”

Health

They also tended to focus on the needs of the care recipient rather than own needs. Some experienced health issues because they put off their own health checks.

“ Me and my mum both have anxiety and yeah, just constantly worrying. Mental health can be a big result and then it just goes around in a circle because that then impacts your caring role which then impacts your mental health, and it's hard sometimes because you don't know how to support yourself. ”

Now and the future

Caring responsibilities influenced the YACs' current and future choices, such as post school options, employment and moving out of home.

Difficult home life can effect the YACs' mood and engagement in school:

“ Yeah I mean it affected school, I mean obviously if mum was in hospital or whatnot. I mean then it affected school – like to bring my mood down. ”

But on the positive side, some YACs thought they learned useful life skills:

“ But at the end of the day I learnt how to get over stuff a lot easier than a lot of people do. So I mean in a way it helped me. ”

YACs sacrificed their own lives to care and had to choose between different activities, such as studying/employment and social life.

“ You're trying to help someone else live their life at the same time as - you sort of sacrifice your own life... - to make sure that someone else's life is not a nursing home. ”

The YACs took account of their caring responsibilities when making decisions about the transition to independent living. Caring responsibilities made it impossible for some young adult carers to consider moving out of home. One said:

“ I'd love to get my own place and then just enjoy that... but I'd be constantly at my mum's and my grandma's. So I just wouldn't have the time to get there. ”

In contrast, one of the young adult carers had recently moved out of home. Her caring responsibilities now predominantly involved monitoring and checking on her mother. Despite being independent and having her own life, the young adult carer's mother was constantly in the back of her mind. She commented:

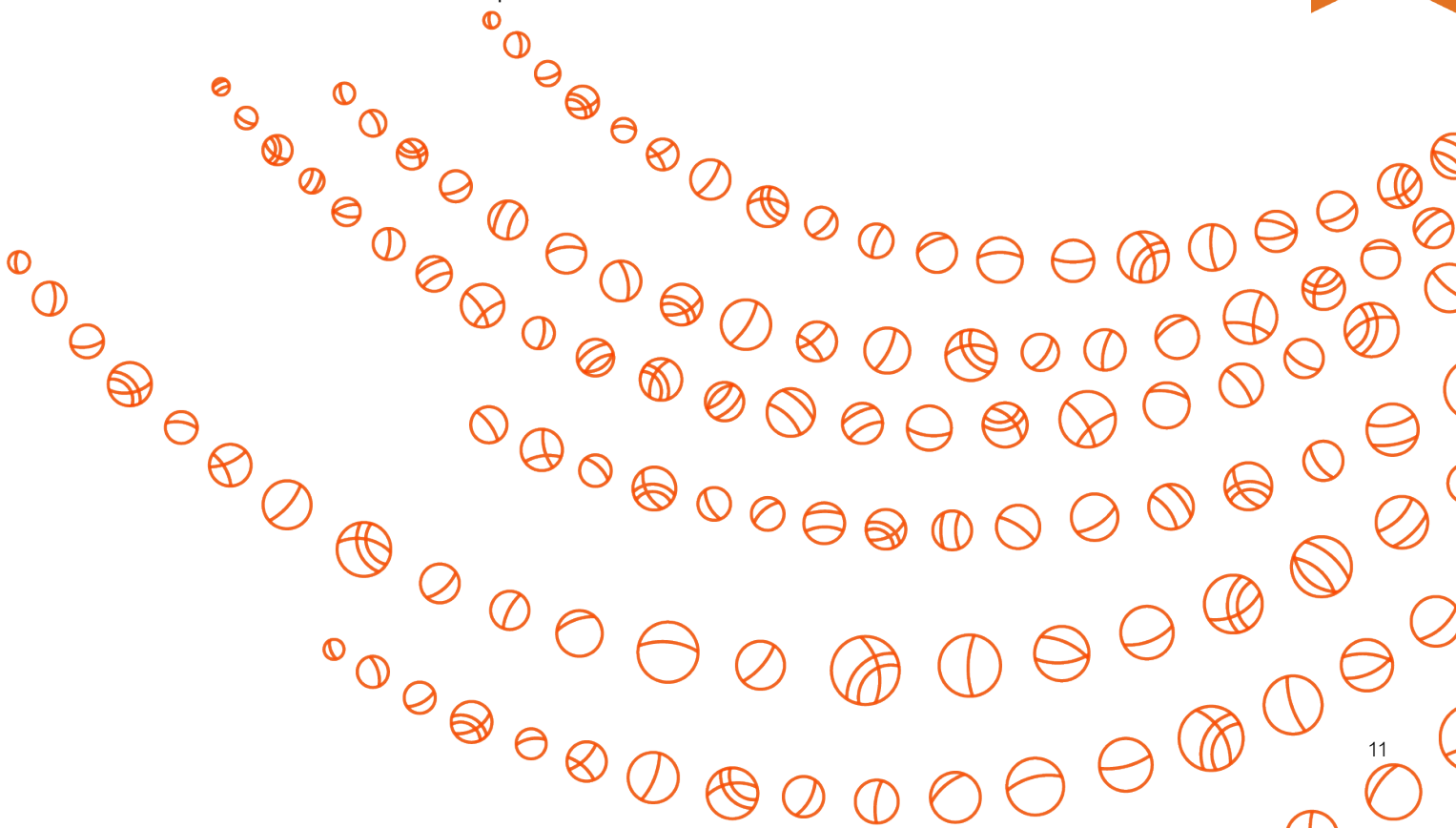
“ Mine’s more of a mental job more than a physical. So I just moved out of home last year and mum’s just up the road from me. So I’m fairly independent but I just have to make sure that her shopping’s done and her washing and all the kind of house chores. But I go out and have my own life and do my own things, but in the back of my mind I’m always worrying, like, is she okay? ”

Impact of caring over time

Although providing care can have a negative impact on YACs participating in different types of activities, it can also have some positive effects. Some YACs felt that their caring role provided them with useful life skills, maturity and a different perspective on life. Others saw providing support to family members and also engaging in other activities was part of normal life. As one young person commented:

“ Yeah it’s just been part of life, I don’t feel like I have to juggle things, it’s just how I’ve grown up with it, you know, it doesn’t feel like it’s out of the normal routine or anything. It’s just been what I’ve done. ”

However, for other young people the impact of providing support had a long-term impact on other aspects of their lives and as one YAC said ‘it puts you behind in life’. This can be especially hard when significant events occur simultaneously such as finishing studying and trying to find a job. Coping with these events can be difficult at this vulnerable time in the young people’s lives as they transition to independent living or from studying to paid work, given their additional caring responsibilities. This can have a cumulative impact on their future.



How should we measure social inclusion for young adult carers?

Indicators to measure social inclusion suggested by YACs

Multiple activities

- Percentage of YACs who are doing more than one activity at a time.
- Percentage of YACs who have to choose between participating in education, working or social life.
- The amount of time allocated to different activities.

Social activities

- Amount of time and how often YACs can get away from their caring responsibilities.
- The type and number of activities YACs do when they are not involved in caring.

Health

- Ratings of physical health and mental health.

Services and support

- YACs' satisfaction with access to respite services.
- Percentage of YACs who access support groups.
- Percentage of YACs with access to family support.

Transport

- Percentage of YACs who have a driving licence.
- YACs' access to transport – public and private.

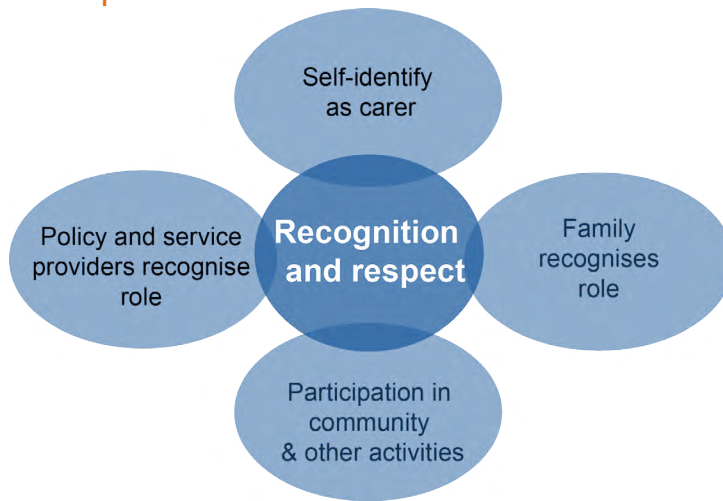
Employment and education

- Percentage of YACs studying their preferred course.
- How easy or difficult was it for YACs to find paid work?
- Percentage of YACs accessing on-the-job training.

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.

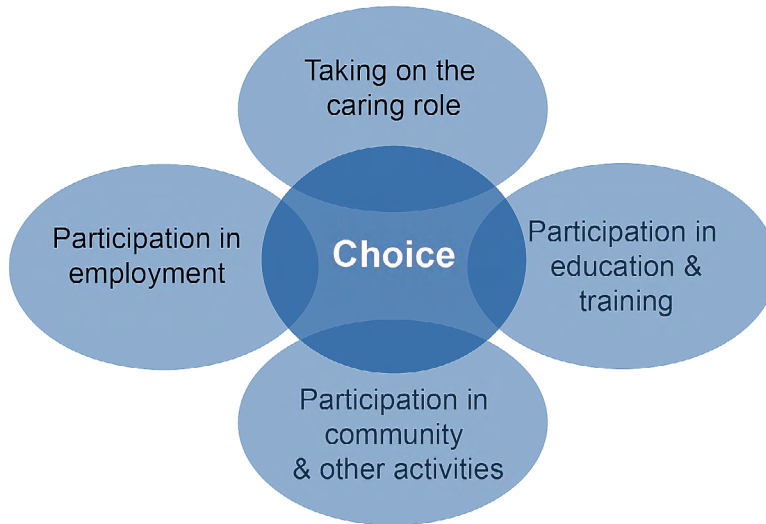
Employment

- 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

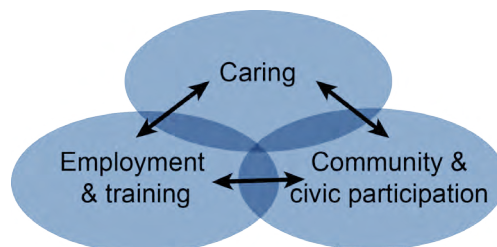


Some carers take on the caring role because there is no other alternative. This lack of choice can have negative impacts on other parts of life, such as entering or keeping a job, education and training, community involvement or spending time with friends.

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.

YACs' suggestions to policy makers and service providers

Finances

- Review the eligibility criteria for young adult carers who are seeking to transition to Youth Allowance. To be considered independent for Youth Allowance requires an 18 month work history of 30 hours per week. Currently, young adult carers aged less than 22 years must provide 'constant care' to qualify for Carer Payment, which has a limit on work or study of 25 hours per week (including travel). Therefore, they cannot be working towards meeting the independence criteria for Youth Allowance.

Social and family support

- More support groups for 18-25 year olds with more regular days to get together; the age limit on some support groups is problematic when they have to move between age ranges.
- Access to enjoyable family activities.

Services

- Better support for care recipients; carers want to know that the care recipient is getting all supports that they can access.
- Improved access to flexible respite services.
- Access to adequate respite to cover the work hours of employed YACs.
- Increased support for early intervention services for care recipients and additional support for people with emotional and cognitive disabilities.

Health

- Access to affordable gym memberships for YACs through financial support or discounted membership.
- Improved access to mental health support and counselling for YACs and their families using a holistic approach.

Transitions

- Increased support, such as case management or advocacy for YACs through key transitions periods eg. from school to work/study and from studying to paid work.

Education

- Access to a place to 'chill out' and focus while at school.
- Assistance to access to face-to-face training and education rather than remote learning.

Employment

- Increased employment opportunities.
- Access to flexible employment conditions.
- Designated positions for YACs.

Rural areas

- Increased transport options - develop a scheme to help YACs buy a car. For example, pay a gap fee similar to Medicare. It could be called 'Medicar' and provide financial help and support to get a driving licence.

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/

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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