



Acknowledgements

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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).

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.

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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

What helps young carers to participate?

Services

- Access to flexible and supportive services, such as Carer Support Services,

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

What makes it difficult for young carers to participate?

Services

-



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:

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 lifeage of YACs who have to choose between 5.7 (o)4.9 (a)un o4.5 (t)





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 effect

Many

YACs' suggestions to policy makers and service providers

Finance

- 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.

Service

- 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.

Transition

- 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.

Real area

- 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:

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