

Queensland Kinship and Care Forum 2

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Address by Sue Elderton, National Policy Manager of Carers Australia

Carers Australia is a national peak organisation which represents carers of people with disability, chronic illness, mental illness, terminal illness or who are frail aged, whatever the age of the carer or of the person being cared for.

- Young carers for us are young people under 25 who provide care for one or more family members with one or more of the conditions I've just described. The nature of that care can be very far-reaching as I'll describe.
- According to the 2018 Australian Bureau of Statistics' Survey of Disability, Ageing and Carers(SDAC), there were about 20,000 young carers under the age of 15 in 2018 and about 87,000 between the ages of 15 and 24. Not all these young carers are what is known as primary carers, those who provide the most substantial amount of care to someone, but about 7000 of the 15 to 24-year olds are.
- Our interest in young kinship carers was piqued when Megan Mitchell and Meredith Vasily can to visit us in November to talk about some of the similarities between our kind of young carers and young kinship carers who took on responsibility for the upbringing of children of a relative who was unable to care properly for them themselves and the lack of supports for those young carers, especially if they weren't involved through the child protection system.

Differences

- There are of course differences between what I will call our kind of young carers and young kinship carers.
- One is the age differences I've mentioned. I don't imagine there are too many young kinship carers under the age of 18.

- Another is that our kind of young carers will often be caring for adults (usually a parent), and sometimes also siblings with disabilities and health problems.

Similarities

However, in comparing the experiences of young kinship carers and those of the young carers we represent, they have much in common.

- For many young carers, it's not just a matter of providing personal and emotional support to someone who is disabled. It can often also mean taking on responsibility for maintaining the house, taking on extensive responsibility for the daily support of the younger children, making medical and other appointments, managing household finances, accompanying members of their family to these appointments and so on.
- So just to provide you with an example taken from our Young Carer Bursary applications (and this story is far from unique):

“I am a 14-year-old Aboriginal boy. It is just Mum, me and my six brothers living at home. I have been caring for my family since I was 8 years old. Mum suffers from drug addiction and mental illness.

Because Mum is sick, it is up to me to get my brothers up and ready for school, including making lunches, breakfast, getting them ready and getting them to school. I also have to take them to appointments, clean the house, make dinner.

I also care for Mum which includes personal care, and providing heaps of emotional support. I get worried about keeping everyone safe and sometimes I can't sleep from worry and being scared. This year especially I have found it hard to attend school properly because I worry about Mum and need to help her.”

- According to the 2016 Census, about a quarter of young carers come from single parent families. They are also often dysfunctional families. The dysfunction often occurs as a result of the impact on relationships of a partner or a child acquiring a mental or physical disability or both. It is not uncommon for this development to fairly quickly result in the break up a relationship.
- Many studies and surveys of young carers highlight that they often get no support from the extended family.
- They tend to struggle with high levels of anxiety and exhaustion.

- Their role is not well recognised or understood within the wider community.
- They can become extremely socially isolated. They are often not in a position to share the same kind of social activities or interests that are available to their non-carer peers. They feel they have little in common with other people of their age.
- Frequently their education and their employment prospects are very adversely affected by the caring role.

Government support

But the big difference between our kind of young carers and young kinship carers seems to be the level of support from government. And I've been asked here today to describe what kinds of supports are available to the young carers we represent. Some of this comes from state and territory governments and, as a national organisation, we are not entirely up-to-speed on these services.

But the big, Australia-wide support services come from national government.

I should point out that this level of recognition of young carers was not intuitive and didn't come easily. It has taken many years of research and advocacy, Also I think an important element of this recognition is the in-depth data which has emerged from the Australian Bureau of Statistics ongoing Surveys of Disability, Ageing and Carers which began in the late 1990s, From what I've read, this level of research is lacking in the kinship carer space.

Starting with financial support:

You don't have to have guardianship status or something equivalent to get this support.

- Firstly, there is the Carer Payment available through Centrelink. This payment is not easy to get.
 - You have to meet a household income and assets means test.
 - Then you need to care for 1 or more people who have high care needs scored against disability assessment tools.
 - You need to provide what is known as constant care on a daily basis for a 'significant period' during each day, loosely the equivalent of the hours you would invest in a job.
 - If you meet these criteria you can claim income support of \$850 per fortnight (about \$200 less if the person you are caring for is also on a pension.)

Difficult as it may be to get the Carer Payment, 8370 young carers between 18 and 24 were receiving the Carer Payment in September last year.

- Then there is the Carer Allowance which is a payment to assist with the additional costs of caring.
 - This is worth \$131 a fortnight which you can get for each person being cared for. You still need to provide about 20 hours of care a week. But the means test is very generous. It cuts out at \$250,000 household income per annum. Everyone on a Carer Allowance (which is available to the carer for each person being cared for) gets a one-off supplement of \$500 per year for each person being cared for. There were over 10,000 young carers receiving the Carer Allowance last September.
- Other, more modest, financial assistance is available through the Young Carer Bursary, which is available to 1000 students a year. It is not intended to cover fees. It is a \$3000 payment to assist with other costs of education such as books, computers, the costs of staying online, clothes, excursions, tutoring – in fact what it can be spent on is pretty open-ended. However, its availability is clearly very restricted.
- Another discretionary payment of \$3000 per year will be available to carers in April when a new national carer support model is rolled out. 25% of these payments will be available to young carers. However, since the number of such payments are capped at 5,000, there clearly isn't much to go around.

Service supports

In 2005 the Federal Government introduced a Young Carer Respite and Information Services Program.

- It was quickly discovered that providing respite for young carers didn't fit the model of respite services available to adult carers, where the person being cared for often went into residential care or other dedicated respite facilities providing over-night or weekend care, or where they might participate in a day care program.

What worked better for young carers was something that had a respite effect. For example, getting paid care in the home, particularly around stressed periods in the education cycle. Or respite camps and other events which the young carers could attend, getting them away from home to do an enjoyable activity and mix with their peers. Evaluations over time showed that this type of assistance went over very well with young carers and helped address their emotional distress and sense of isolation.

- The information and referral part of the program had a number of elements which evolved over time. Young carer case workers provide assistance with identifying and accessing mainstream supports which can help address the needs of the young carer or those they are caring for. In some cases, the young carer service providers formed collaborative partnerships with other organisations such as mental health services (for example, Headspace), Centrelink, youth services and some schools.
- Unfortunately, when the bilateral negotiations between the national and state governments on contribution to the costs of NDIS happened, the national government threw the young carer funding as part of its NDIS contribution. We advocated fiercely against this and had a partial victory. The information services and referral remained, but the respite funding didn't.
- In April, as I've mentioned, the new national carer service model will be introduced. This model is designed to meet carer demand whatever age of the carer is seeking for or the age or disabling condition of the person or people they are caring for. This means there will be counselling, coaching services, and peer support for young carers as for everybody else. Access to emergency respite will also be available. However, in addition, in the last Budget the Government introduced a young carer worker allocation for each regional service delivery organisation and, as I mentioned earlier, access to 25% of the consumer directed financial packages.
- There is also online counselling (ongoing phone support), online coaching and education programs available on the national Carer Gateway.
- In terms of online support, young carers are comfortable and familiar with connecting with one another online. Carers Australia has established a Young Carer Network on which carers can share their stories. It also provides information. We have had 28,000 hits in the last 12 months and have 6,300 registered users.

In my opinion most if not all of these supports should also be available to young kinship carers. In conversations with Meredith and Meagan we discussed whether one way to go was to advocate for kinship carers to be included in the broader definition of carers in the National Carers Recognition Act. The idea doesn't jar. However, I think it would take some time to achieve unless it became an election promise for an incoming government.

