

## We're all in it together: supporting young carers and their families in Australia

**Tim Moore** BA M Child&Adol Welf, M Youth Studies and

**Morag McArthur** Dip.Welfare, BSocSci (Hons), Postgrad Cert Higher Ed Teaching, PhD

Institute of Child Protection Studies, Australian Catholic University, Watson, Australian Capital Territory, Australia

### Correspondence

Tim Moore  
Research Fellow  
Institute of Child Protection Studies  
Australian Catholic University  
Watson  
ACT  
Australia  
E-mail: tim.moore@acu.edu.au

### Abstract

Although recent initiatives in Australia have attempted to respond to the needs of children and young people with care responsibilities, many continue to be unable to access responsive supports. A qualitative, exploratory study was conducted to identify the current needs and barriers to services for young carers and their families in Canberra, Australia. This paper focuses on a range of family, service and systems level issues that impede young carers' access to services. The findings are based on semistructured, face-to-face interviews conducted with 50 children and young people with care responsibilities. Purposive and snowballing sampling were used to recruit the sample. Peer researchers were involved in the development of the research parameters and conducted and analysed interviews. Young carers in this sample reported high levels of need but low levels of support provided formally and informally by their extended families and the service sector. Major barriers to support included reluctance within families to seek assistance for fear of child removal, negative intervention and increased scrutiny; the families' lack of awareness of available services; a lack of flexibility and responsiveness to the holistic needs of families; and a lack of service collaboration. The importance of recognising the specific needs of each member within the family unit was particularly highlighted as was the need for responsive and co-ordinated service supports.

**Keywords:** accessibility, barriers, family-centred practice, holistic support, young carers

**Accepted for publication** 28 March 2007

### Introduction

There has been a growing recognition that families affected by illness, disability, alcohol or other drug use and mental illness often need a range of supports to ensure that cared-for relatives have their needs met, and that the negative impacts of caring are reduced for other family members. Studies have consistently shown that large numbers of families either do not receive any assistance from the service system or do not receive adequate levels of support to meet their needs (Low *et al.* 1999, Lundh 1999, Enduring Solutions 2003). The Australian Survey of Disability, Ageing and Carers (1998) showed, for example, that approximately one-third of primary carers who needed respite care had received it in the 3 months preceding the study (cited in Enduring

Solutions 2003). The first survey needs in Sweden found that around one quarter of carers felt that the level of practical support that they had received from healthcare and home-help professionals had been unsatisfactory (Lundh 1999). These studies are consistent with similar research conducted in the UK (McGrother *et al.* 1996), the USA (Houde 1998) and elsewhere and highlight that our systems are currently not meeting the needs of people with disabilities or their carers.

Although we have some idea about the use and non-use of services by carers generally, there continues to be little understanding of the particular service needs and support experience of children with caring responsibilities. These 'young carers', who are under 18 years, appear to assume similar levels of care responsibilities to adult carers but can be more vulnerable due to their age and

developmental needs. Other than national surveys in the UK that have focused on young carers' engagement with young carer support programmes, there has been limited research that has attempted to understand their interactions with the broader service system (Dearden & Becker 1998, 2000), the barriers to the provision of effective services for their cared-for relative, or strategies to improve outcomes for their families.

In 2005, a research project was commissioned in the Australian Capital Territory (ACT) to develop an understanding of the support needs of young carers and their families and to gauge the level of services accessed by families where children assumed care responsibilities. The project was funded by the ACT Department of Disability, Housing and Community Services and conducted by the Youth Coalition of the ACT with assistance from the Australian Catholic University. The project aimed to capture young carers' experiences of services, identify current service gaps and to formulate strategies to overcome potential barriers. This paper summarises the key findings of the project.

### What do we know about young carers?

Since the mid-1990s there has been a growing awareness of the existence and specific life experiences of young carers in the UK and Australia and, in more recent times, in New Zealand, Malta, The Netherlands, Germany, Canada and southern Africa (Becker 2005). During this period, governments have commissioned research reports, held conferences and developed policies to identify and respond to young carer's needs.

From these activities, it has been estimated that between 4 and 10% of children and young people will regularly care for an ill or disabled relative during their childhood and adolescence (Gays 1998, Cawson *et al.* 2000, Becker 2006). These young carers may assume personal and intimate care responsibilities for their relatives, ensure safety, provide emotional support and monitoring, maintain households, supervise younger siblings or assist others to do so (Carers Australia 2002). These caring tasks are often provided without supervision or assistance and are often similar to those undertaken by adult carers. Young carers report caring from the age of 6 years and will care into their adulthoods although most young carers are aged between 10 and 13 years (Access Economics 2005, Becker 2006).

Although the experience of young carers is not an homogenous one, Australian and international research suggests that caring can affect young people's physical and emotional well-being, their connections with peers and the broader community, their family relationships, their educational and employment outcomes, their family's financial stability and their opportunities for

the future (Marsden 1995, Aldridge & Becker 1997, Carers Australia 2002, Halpenny & Gilligan 2004). More recent studies have also focused on the positive aspects of caring (including young people feeling a greater sense of purpose, or capacity to deal with challenges; the ability to empathise with others; stronger family relationships and developed helping skills). These studies emphasised that these positive impacts are mitigated by the level of support that children are provided with (Halpenny & Gilligan 2004, Becker 2005, Morgan 2006).

The UK Young Carers Research Group argues that it is the level of support that is provided to families that determines whether a young person will assume care responsibilities for their relative, the level and nature of care provided and the negative impacts that these care responsibilities can have on the child or young person's life (Dearden & Becker 1998). What has not been determined in the literature, however, is the extent to which young carers and their families are able to access services and what are the key barriers that hinder them from receiving appropriate supports.

Interestingly, almost all of the research conducted has been with children and young people who are engaged with the service system. Previous studies have relied heavily on young carer-specific programmes to recruit from within their current client group. What is missing therefore is the voice of those who have not been identified as young carers and who have not been able to access appropriate levels of support for themselves or their families. This is a significant oversight as we realise that those families most marginalised are often in greatest need of assistance but least likely to access appropriate supports.

### Methods: talking to young carers about their experiences

In 2005, the peak body for youth affairs in the ACT, the Youth Coalition of the ACT, was funded to talk to young carers about their experiences of caring and the services that support them. The project was a qualitative, exploratory study that attempted to understand what impeded a family's access to responsive and appropriate services and how the system might better facilitate their engagement.

Adopting a participatory approach to research, the project trained a group of young carers as peer consultants who assisted the research team shape the way that questions were constructed and the themes that the research should explore. In addition, the peer consultants influenced the language of the research, ensuring that it was appropriate and 'youth friendly'; and assisted the research team engage hard-to-reach groups and encouraged active participation of diverse youth groups in the research project. This approach was congruent with good practice principles (see Crane & Brannock 1996,

France 2000) and recognised that young carers were best placed to understand and connect with others who had similar experiences to themselves. The young carers were trained in social research methods and were supported to conduct interviews with their peers with the support and supervision of youth researchers who also transcribed young carers' responses.

The project received ethics approval from the Australian Catholic University and was developed in a way that protected participants' privacy and confidentiality, attempted to minimise power imbalances, and gave young carers control over their involvement in research activities. Before conducting interviews, parents and children were briefed about the nature and scope of the project, completed consent forms and were reminded about their rights within the project – including the right to disengage from the process at any stage.

Transcriptions from the interviews were analysed and key issues were identified. Researchers then carried out a content analysis of the data, which involved identifying coherent and important examples, themes and patterns (Strauss & Corbin 1998). Researchers then discussed the themes with the peer consultants to ensure that they had properly understood young carers' responses.

### Participant characteristics

A total of 50 interviews were conducted with children and young people aged 9–24. Of these, 26 respondents were male, 24 were female, nine identified as having an Australian Aboriginal or Torres Strait Islander background and 10 came from culturally or linguistically diverse communities.

Many of the young carers were recruited through existing young carer support and recreational programmes. In addition, the peer researchers used snowballing techniques to identify and engage other children and young people with care responsibilities that had not previously accessed services – from within their own peer networks and through other mainstream youth programmes.

Young carers in the sample most often cared for a mother ( $n = 26$ ), a father or stepfather ( $n = 16$ ) or a brother ( $n = 19$ ). Fourteen of the young carers cared for more than one of their relatives. Young carers in this study most often cared for a relative with an alcohol or other drug-related issues ( $n = 25$ ), a mental health problem ( $n = 18$ ) and/or a physical disability ( $n = 13$ ). One-third of young carers cared for relatives with multiple conditions or disabilities.

Most young carers in the sample had been caring for extensive periods of time with over half caring for '7–10 years', 'more than 10 years' or 'always', making up more than 60% of most children's lives.

Compared with other studies and from extrapolated data from the Australian Bureau of Statistics, the sample group included a higher proportion of children caring for a relative with an alcohol or other drug problem, those from an Aboriginal or Torres Strait Islander background and those caring for more than one relative. The sample, however, appears to be congruent with the growing body of anecdotal evidence that asserts that families from vulnerable communities are less likely to request support and are therefore hidden within the care population (Morrow 2005).

### What young carers believe they and their families need

#### Supports for their cared-for relative

Young carers in the study felt that the best way that services could support them was to better support their cared-for relatives. This argument is congruent to that of writers such as Morris (1997), Becker (2005) and others who maintain that if the needs of people with disabilities and illnesses are fully met by the service system, then children and young people's need to assume inappropriate or potential detrimental care responsibilities would be significantly reduced.

The supports that young carers most often identified included assistance with personal and intimate care tasks (such as changing dressings, bathing and providing medication) and support with mobility and transport. Young carers caring for siblings or other relatives with an intellectual disability or mental health condition also reported that assistance with supervising, monitoring or 'keeping relatives' safe were also significant – particularly if the young carer was attending school or needed to spend other periods out of the family home.

Most often, young carers felt that their greatest need was for respite (be it in-home or residential) – particularly during times when the young carer was sick themselves, during peak times at school or when the family was experiencing conflict. They felt that having someone assume responsibility for their family member would greatly influence their ability to participate in education, employment and social opportunities.

In addition, young carers called on more personal and emotional support for their cared-for relatives who felt distressed, upset or guilty about being reliant on them for assistance. This support would also be invaluable for parents who felt generally depressed or anxious:

It's so hard for Mum. It's not easy being sick and sometimes it gets too much for her.

Dad wishes he didn't have to rely on me. He gets upset and tried to do things for himself when he really just can't. I tell him that it's OK but he gets upset.

### **For the family**

Young carers also believed that assistance for their families would reduce the level of stress, conflict and family breakdown that had a flow-on effect to their own lives. Young carer participants identified that due to the increasing costs of medication, health care and fee-for-service support, their families often suffered financially, often limiting their own access to community life, education and recreation.

Young carers felt that it would be useful for their families to be offered family-centred assistance, such as mediation and counselling, and also opportunities to participate in 'normal', relationship-strengthening activities, such as family holidays and 'fun' family nights where they could spend positive time together. In addition, they hoped that assistance might be available for other family members to 'get out' and reconnect with their communities. As one young carer noted:

Since Dad had his accident, Mum has never gone out.

### **For themselves**

Young carers in this study were reluctant to identify their own needs, particularly when they believed that they were putting these above those of other family members. However, when asked to identify what other young carers might need, young carers argued for assistance for them to participate in community life, to attend school and have opportunities to have a break from their care responsibilities. Such supports might include personal and peer support activities (including counselling, groups and skills programmes), information on illnesses, disabilities and caring, flexible educational opportunities and formal respite.

### **What supports are young carers and their families currently receiving?**

#### **Support from within the family**

Many young carers see themselves as being part of a 'care team', where other family members assisted them with care responsibilities. Young carers placed significant value on the support that they were receiving from within their families and often reported feeling supported and close to other caring relatives.

Of those who identified family members who provided them with assistance, only a few could identify ways that families directly assisted them and responded to their individual needs. This was often because the family's focus was primarily on the cared-for relative's needs and, as such, because energy was placed on ensuring

that they were supported. Young carers appreciated this assistance but sometimes felt 'hidden' and unable to seek help.

Although assistance from family was common, 12 young carers in this sample could not identify anyone within their nuclear or extended family who currently provided them with support. Some identified aid that had been provided in the past but reported that help had slowly declined. As one young woman put it:

My grandparents wrote off my Mum and told me to get fucked.

In such situations, young carers reported that either their well parent (usually their father) or older siblings had left home because they 'could no longer cope' with the caring role or because they felt 'burnt out'. In four of the families, the young carer who was interviewed was the second or third child in the family who had taken on the caring responsibility, with other sibling leaving home feeling unable to continue.

### **Assistance from the service system for the cared-for relative and their families**

Thirteen of the 50 young carers interviewed reported that they received support from the service system, including respite, in-home occupational therapy or rehabilitation support, and community nursing. These young people found that the assistance was useful: relieving them of their care responsibilities, resolving their relative's health issues and giving the whole family a break. However, most of the young carers felt that the level of support provided was limited (only five young carers could identify a service or support that they could access more than once a month and only seven could identify a support that was not once-off) or not of high enough quality for it to meet their needs:

We had a worker once who just sat down all shift and did nothing. My brother was going off and I had to calm him down because the worker wouldn't. I was supposed to be taking a break – but I was even more stressed because I couldn't trust them.

Young carers also identified other services that focused on the broader family, including help with housework, emergency relief and service co-ordination and transport. Although they found these supports useful, young carers felt that because they were often once-off or otherwise time limited, their effectiveness was reduced (Table 1).

### **What keeps young carers and their families from receiving support?**

Young carers in this sample believed that there were a number of reasons why their families did not seek

**Table 1** Use of services by young carers and their families

Services provided	No. of respondents	Percentage
<b>For cared-for relative</b>	<b>13</b>	<b>26</b>
Respite care	7	14
Occupational therapy or rehabilitation	4	8
Community nursing	2	4
No support	37	74
<b>For family</b>	<b>10</b>	<b>20</b>
In-home support	1	2
Emergency relief	4	8
Care and protection	5	10
No support	40	80
<b>For themselves</b>	<b>30</b>	<b>60</b>
Personal support	3	6
Accommodation assistance	1	2
Counselling	1	2
Social/recreational	28	56
No support	20	40

support or access assistance from programmes. In addition, they believed that appropriate and responsive programmes were often unavailable or inaccessible. Some of the reasons for this situation included the following.

### Service design issues

Twenty-three young carers believed that their families were unable to receive the supports they needed because available programmes were not of high enough standard to inspire family confidence, did not currently meet the family member's needs or because they had had negative experiences in the past.

We got burnt – they treated Mum like shit and we don't want to have anything to do with them anymore. We need help but we just can't trust them – and we don't want Mum to have to go through it again.

### Access issues

Seventeen young carers felt that because services did not provide transport ( $n = 4$ ), were too far away ( $n = 4$ ) or because they were too expensive ( $n = 9$ ), they were not accessible. This was particularly the case for families who were experiencing poverty and those who were geographically isolated from services and supports:

They used to come around and help but then they started charging us and we couldn't afford it so we had to stop.

### Service promotion issues

Young carers reported that they were often unaware of what programmes were available ( $n = 15$ ) or how to access them ( $n = 8$ ). Often without the time, skills or 'know-how' to identify available supports, young carers

reported that they just could not get the assistance they needed. Of those who were aware of services that were available, only a limited number felt that they were entitled to services or were eligible for assistance:

There needs to be more information so we know how to get help. You ring heaps of places and 'cos you don't know the exact details you can't help. That's crap!

### Reluctance within the family

Families in the study were often reluctant to seek or accept assistance. This was the major barrier for young carers ( $n = 48$ ) with many suggesting that families believed that even though they were struggling, they could either cope without outside help ( $n = 20$ ), felt guilty about asking for assistance ( $n = 9$ ) or preferred caring to be a family issue with all responsibility presumed by family members ( $n = 10$ ). Young carers also reported that their families were concerned about seeking assistance because they did not want to feel judged, criticised or over-scrutinised by the service system. Many families were also reluctant to seek assistance because they were afraid of involvement with the care and protection system, particularly child removal if their family's circumstances were uncovered.

### What keeps young carers from receiving the support that they need?

Young carers identified a range of reasons why they would not let others know that they were caring at home. These included:

- *Young carers do not identify themselves as young carers and therefore do not realise that there are others in*

the community with similar experiences, or that there are services to support them.

- *Fear of unwanted intervention* kept many of the young carers from disclosing their experiences to those around them. In particular, they felt their families feared child removal and/or unwarranted judgement and ridicule of the whole family unit.
- *Fear of bullying and harassment* was a common experience for many of the young carers, particularly in the schoolyard and classroom. Many of them noted that unless the stigma around illnesses and disabilities (particularly mental illness and alcohol and other drug use) was addressed and the chance of harassment reduced, they would not identify as being a young carer.

I don't wanna be bullied plus I don't want my Mum to get greasies [bad looks] or for people to think bad about her.

- *Lack of awareness and recognition* was raised as an issue by young carers who reported times when they had identified as a young carer but were met with disbelief because people did not know that young carers existed. For some this was quite dramatic.

She said 'all families have problems, stop hiding behind your Mum'. She thought I was making it up to get out of homework ... That hit me hard.

- *Bad past experiences* were raised by a number of young carers who had experienced the aforementioned issues and were reluctant to repeat their experiences. Others reported times when identifying had not been positive, including times when their confidentiality had been broken.

My Mum was sick and I was coping so I told my teacher so he'd get me off homework. But he gave me more 'cos he thought that would take my mind off things.

In addition to personal reasons for not seeking support, young carers identified a range of service barriers that restricted their access to assistance. These included:

- *Services do not always acknowledge or know how to deal with young carers*, which meant that many young carers did not receive any support (including referrals) from disability, mental health, alcohol or other drug or youth services, which each asserted that young carers did not fit within their service targets and was the responsibility of other services and sectors.
- *Services do not appear to have a good understanding of the family issues of their clients* and therefore do not take into consideration young carers when developing or providing services to children and young people. This became quite obvious for the research team when they were recruiting young carers, with

representatives of a large number of services saying that they were not aware of any children or young people accessing their supports who were in a family affected by illness, disability, mental or alcohol or other drug issues, when, on further investigation, a large proportion were.

- *Young carers are not recognised as target groups or defined as 'at-risk'* in programme guidelines for mainstream youth services, which means that many do not receive the services and supports that they need (i.e. counselling, case management, advocacy, family assistance, education support).
- *Services are not flexible enough to be accessible or to meet young carers' needs* when they do not provide transport, are not open after-hours and on weekends, or when they require an ongoing commitment from young carers who often do not know when they will be needed at home.
- *Services are not affordable* and therefore are inaccessible to the large number of young carers experiencing poverty if they charge, or appear to charge for services.
- *Services that met their specific needs were not available.* This was a particular issue for children under 10, those caring for a relative with an alcohol or other drug issue or an undiagnosed mental health problem. Young carers who had relinquished their care responsibilities or who had been separated from their families also felt that supports to help them resolve feelings of loss, grief, guilt and disconnection, or to help them rebuild relationships were non-existent. This was particularly the case for former young carers who had entered into the juvenile justice and care and protection systems or who were homeless.
- *Young carers do not know what services are available or how to access support.* This was probably the most commonly raised issue for young carers who wanted and needed support but were not aware of where to go or how to get the help they needed.
- *Young carers do not have the time to access external supports* because they are often needed at home.

In addition to these family and service-level issues, young carers also identified that community attitudes towards childhood, disability and families often restricted their access to, the types of supports provided, and the way that help was offered.

- *Attitudes towards disability, illness, alcohol or other drug use and caring* were identified as a major barrier for children and young people accessing services. Many felt that they could not talk to their peers, their teachers, or seek support from services for fear of bullying or harassment. Many young carers gauged

the amount of understanding they would receive from others by the way they spoke, joked and interacted with people with disabilities.

I wasn't invited to places because they said I had a 'retarded' brother and people thought I was retarded myself.

- *Blame and shame* were significant barriers for young carers and their families, particularly when caring for a sole parent. Driven by the false belief that parents with disabilities, illnesses and conditions are not able to effectively parent their children, community attitudes often alienate and stigmatised affected families who become reluctant to identify themselves or seek support. Feeling guilty or ashamed of the responsibilities their children assume because of a lack of external supports, families report feeling disempowered and disconnected from the community.

It's like they think that we don't get a childhood – that we don't get what we need – and that it's our family's fault that someone should be sick.

- *Lack of understanding* about the dynamics of caring were identified by many young carers who felt that while services problematised their experiences, by seeing them as victims or as exploited children, or conversely as 'angels' or 'heroes' with no room for failure or need of support, they could not seek or accept support. Young carers wanted their experiences to be acknowledged, and just as importantly, for services to be put in place to increase their family's capacity to respond to challenges.

This is my family. I'm a carer because I love my family. Don't pretend they're not there or think they're a problem, weighing me down, because I'll just fire up and tell you to get fucked.

### **What are the implications for supporting children and young people with caring responsibilities?**

In the past, and to the concern of the Disability Rights Movement (Keith & Morris 1995, Olsen 1996), the focus of the young carer movement, and the design and development of young carer supports and services have focused primarily on the child or young person in isolation of the family unit. Although young carers in this project saw the great value of receiving specific interventions for themselves, such as camps, support groups and mentoring, they asserted that resources and assistance must also be provided to their cared-for relative and broader families if the negative impact of care were to be reduced. They called for a general increase in the levels of resources and supports provided to community members who were frail aged, had illness, disabilities, mental health or alcohol or other drug issues as:

... the most critical factor in determining who cares and what they do appears to be the availability of support from outside the family itself ... [T]he provision of services ... seems to decrease the level of caring provided by children. (Dearden & Becker 1998, p. 69)

However, they also called for additional understanding and recognition from primary health providers about their needs and issues. Young carer services often worked with them but excluded their families. Because of this many children and young people in this study felt invisible to the eyes of service providers who supported their cared-for relatives without taking into consideration their needs or wants. As Price (1996) writes, to a large extent, many disability services focus 'on the adult with the disability, without reflecting how the adult's disability may impact on the functioning of the entire household.'

The problem also strongly reflects organisational and service system structures that are 'single input services' based on categories of funding (Scott 2005). Gays (1998) presents a further reason and argues that non-youth-service providers often do not feel comfortable working with young people or the myriad of complex issues that they face – 'we don't know how to treat them so we largely ignore them'. To be effective therefore young carer services must work closely with primary health providers and develop co-ordinated whole-of-family responses together.

Families also need to be supported to access services that meet the needs of all family members. To do this, services must respond to family fears around child removal and act in a way that acknowledges their strengths and resources and minimises further stigmatisation and feelings of blame or shame. Families need opportunities to identify how caring impacts on each family member; particularly children with care responsibilities. They need to be supported to find appropriate services to meet their needs, both individually and as a group. This approach fits with the relatively recent concept of 'family-centred inter-agency collaboration' that argues for not only a family-centred approach but also the recognition that services need to work together to ensure family's needs are met (Walter & Petr 2000). Until these family-based barriers are addressed, the opportunities for young carers to receive supports to enhance the positive impacts and to reduce or overcome the negative impacts of care are significantly limited.

### **Conclusion**

Young carers provide significant levels of care within their families, often at a cost to their health, well-being, participation in community life, and to their safety. However, the children and young people who participated

in this research project also reported positive impacts of care – the development of skills, life experiences, esteem and resilience – when and if appropriate supports are available to them and their families. As such, communities and their services must identify and respond to barriers restricting young carers' access and ensure that appropriate help and care is given wherever possible.

### Acknowledgements

The authors would like to acknowledge members of the Young Carers Research Team, Jayme Gray, Rebecca Johnstone, Morgan Pettit, Madeleine Nield and Jess Butler, the peer researchers who helped gather much of the material presented in this paper. This project was conducted by the Youth Coalition of the ACT and was supervised by the Australian Catholic University. The project was funded by the ACT Department of Disability Housing and Community Services.

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