

## The hidden young face of care

MARIA HUDDLESTON AND DEBORAH WEST

### Abstract

*Young people who provide unpaid care to someone with an illness or disability in their households can remain unrecognised by practitioners within the health and social care system as the focus is usually on the presenting individual or those who require care. Practitioners working in the health and social care system should have knowledge and awareness of who young carers are and their circumstances. This article seeks to raise the profile of young carers so that practitioners are able to recognise and provide holistic care to the family and provide resource and support opportunities for young people who provide care.*

**Key words:** *Young carers, practitioners, health and wellbeing, human service system*

### Introduction

This article will explore the phenomenon of unpaid, informal care in Australia, with a focus on young people providing family care. Young people who provide care in their home are vulnerable to being overlooked and remain hidden in Australia, as informal family care is often interpreted as an expectation of family commitment (Becker 2007; Cummings, Hughes, Tomy, Gibson, Woerner and Lai 2007). This can create structural domination and oppression within service provision.

### Background

While the unpaid caring phenomenon has existed for centuries, informal care has only really been acknowledged in Australia through initiatives and policies in the last few decades, including the Carers Recognition Act 2010, the National Carer Recognition Framework, Carer Payment and Allowance through Centrelink, National Carers Week, and specifically to the Northern Territory: the Carer Concession Scheme and The Northern Territory Carers Charter.

Within Australia informal care comprises 77% of total community care (Australian Bureau of Statistics 2003; Carers Australia 2001), and while this is an extremely vital contribution within the community, it is largely unrecognised and undervalued (Duckett 2000). The value

of informal care provided by Australians is estimated at a total replacement cost of \$30 billion annually (Australian Bureau of Statistics 2009) and is estimated at a relative value of 0.6% of the gross domestic product (between 2004-2005) (Eagar, Owen, Williams, Westera, Marosszeky, England and Morris 2007). Within an ageing population and with individuals living longer with an illness or disability it is likely the contribution of informal care by family carers will increase in future years.

The focus of this article centres on young carers in Australia who are defined as a young person aged between 5 and 25 years who provides unpaid care and support to a family member or friend who suffers from a disability, mental illness, chronic condition, terminal illness, or who is frail (Carers Australia 2009). Approximately 10% of the Australian population aged between 15 and 25 years provide unpaid, informal care (Carers Australia 2001), and two thirds of this population are the main or only source of care and support (Carers Australia 2001). When considering the ages and developmental stages of children and adolescents, it is quite alarming to think that a large percentage of Australian children provide care during a significant developmental time.

A large proportion of young carers are of culturally and linguistically diverse backgrounds (Hill, Smyth, Thomson and Cass 2009), and within Australia Indigenous Australians are 1.8 times more likely to provide informal care than non-Indigenous individuals (Australian Bureau of Statistics 2008). Indigenous young carers account for the largest proportion of young people who provide care in the Northern Territory and other remote parts of Australia (Hill et al. 2009). While almost a third (32%) of the Northern Territory's population is Indigenous (Australian Bureau of Statistics 2006), it is evident that these individuals are overrepresented as informal carers. This may be attributable to the early onset of chronic illness within the Indigenous population (Australian Bureau of Statistics 2008), and a cultural outlook of providing care responsibilities as an extension of family duties (House of Representatives 2009).

The prevalence of young carers is further expected to increase with an ageing population, advanced medical technology allowing people with an illness or disability to live longer, changing social structures (individualisation and privatisation of health care), changing family structures (one parent households), and changing economic conditions (working parents). As young people often cannot contribute to the family financially, they are sometimes given no alternative but to assume a carer role within their household (Aldridge and Becker 1993).

Young carers assume adult-like responsibilities which include: shopping, cleaning, cooking, managing finances and dealing with financial issues, attending health appointments, taking care of and raising other siblings, and negotiating with service providers (The Carers Association of SA 2005). Young carers also assist the care recipient with personal care needs including dressing, bathing, toileting, assisting with mobility and administering medication (The Carers Association of SA 2005). These children are often depended upon to listen to

medical problems, understand psychosocial difficulties, and interpret where English is not the first language (The Carers Association of SA 2005). It is evident that young carers may assume complex and quite confronting tasks while they are young and that they will likely be depended on by other family members to assist with aspects of health and social care.

Care responsibilities become more involved and acute as young people grow (Dearden and Becker 2004), and these are likely to advance above and beyond age appropriate responsibilities (Hill et al. 2009). Children and young people who provide care find they make sacrifices which impact on their education, social interactions, health and wellbeing (Heron, 1998). These individuals are more likely to live in low-income, rental and financially insecure households as few adults who receive care from their children hold paid employment (Hill et al. 2009; Aldridge and Becker 1993). Many young carers may also not have the support and nurture from family members as the focus is on the care recipient. Increasing responsibilities within the household may impede young carers' opportunities to explore a personal identity (Berger 2005).

While many practitioners and the broader society remain unaware of the responsibilities and tasks of young carers (Thomas, Stainton, Jackson, Cheung, Doubtfire and Webb 2003), families of young carers have voiced reluctance to disclose information about children's roles in the household. Parents often feel that such disclosure could lead to the involvement of child welfare services in questioning parent capacity to care for their children (The Office of Standards in Education, Children's Services and Skills 2009). Human service practitioners can also be unaware of the situations of these families, concluding that parents have exploited or neglected their children (Moore and McArthur 2007).

As the role of caring falls on young people due to inadequate formal support and intervention from external social structures (Bursnall 2003; Aldridge 2008), this hidden face of care urgently requires attention and acknowledgment by human service practitioners. It is evident that providing informal family care has the potential to impose restriction on adolescent development, and social and educational opportunities (Becker 2003). Care responsibilities can leave individuals socially isolated, suffering poor physical and mental health, and experience a loss of control over daily living which impacts on individuals' diet, self-care, rest and the relationships around them (Gahagan, Loppie, MacLellan, Rehman and Side 2004). This is further exacerbated by the findings of a recent national study which speculates that family carers account for a large proportion of individuals who suffer from depression (Cummings et al. 2007).

These potential negative outcomes of providing family care leave young carers vulnerable. They may experience negative impacts on mental, emotional, and physical health alongside the developmental changes encountered during their transition into adulthood. It is therefore likely young carers will encounter health and social difficulties as a result of their care circumstances before they reach adulthood.

## The Human Service System

As previously discussed, young carers may be required to manoeuvre through the human service system to secure resources and support for the care recipient. As a result of their age, appearance, experience and confidence in interacting with practitioners and navigating the system, these young people are vulnerable to marginalisation and structural oppression. They may be perceived by practitioners as too young to be heavily involved in family affairs or undertake complex adult roles, or may be overlooked as having any involvement at all. This silence is likely to be further enforced particularly as family members may not disclose the young person's involvement in care. This is despite the young carer being ideally positioned to provide information to practitioners concerning daily routines (e.g. diet, physical activity and pain management) which can be used to inform health care plans, monitor progress and provide a holistic picture of home care.

There are also service provision gaps where young carers are overlooked as being affected or impacted on by their care and family circumstances. While organisational funding guidelines and policy restrictions prohibit assistance and support to family carers (Moore and McArthur 2007), it is crucial that young carers do not fall through service provision cracks. Human service practitioners hold an ethical responsibility and duty of care to support and assist children and young people with whom they have contact. This can be extended within practice to include young carers. Identifying young carers within families assists in dismantling the barriers which contribute to hidden family care.

Within regular practice practitioners can ask whether children in the home are affected in some way by the care requirements of the presenting individual. This provides a starting point for conversation around children's involvement in family care. While service provision is bound by organisational roles, funding and policies, practitioners can nevertheless make referrals or provide families with information about local carer-specific organisations which support family carers.

One such organisation which provides direct support to informal carers and their families across the states and territories of Australia is *Carers Australia*<sup>1</sup>. This non-government, not-for-profit organisation is the national peak body for informal carers (Carers Australia 2009) which liaises with all levels of government, policy makers and the general public to provide a voice for carers.

By providing families and young carers with information of available resources and support within the community this could assist and support young people to continue providing effective care within their home. Practitioners within the human service system are ideally positioned to provide families with the opportunity to gain further carer-specific support and

---

<sup>1</sup> Carers Australia website: <http://national.carersaustralia.com.au/>

raise the profile of the widely hidden phenomenon, gaining acknowledgement of young people providing care, and their potential structural oppression and silencing. By further understanding and recognising the responsibilities and tasks young carers assume, as a society we begin to appreciate the contribution these young people make, and their aspirations, hopes and dreams which are impacted on by circumstances beyond the control of surrounding individuals. A study reveals that young carers felt alone, did not know where to go for help, nor were they aware that there were other young people in similar situations (Kambouris 2011). Providing the opportunities for young carers to access carer-specific support and resources works toward alleviating these feelings of loneliness, social exclusion, and helplessness.

Within a society where more young people will be called on to provide family care, where young carers will increasingly care for more individuals and where they are likely to grow in to adult carers due to changing social and family structures, it is critical that these young people are acknowledged, understood and supported. If young people are to have the best opportunities to grow into well adjusted adults they need (and have the right) to be nurtured, supported and understood in their journey. This is particularly important for young carers whose contributions and circumstances otherwise remain hidden.

## **Conclusion**

This article attempts to raise the profile of young carers within the Australian society through a brief description of their roles and responsibilities. While children have provided family care throughout time, it is important the human service system and its practitioners acknowledge the contribution these young people make to society. Furthermore it is critical that practitioners provide vehicles for these young people and their families to gain specific resources and support to assist young carers to grow into healthy adults with the best opportunities for life. This is possible without making drastic changes within service provision, but by merely making a referral or providing families with information of local carer-specific resources or support. Young carers of today are the future family adult carers.

## References

Aldridge, J. (2008) 'All Work and No Play? Understanding the needs of children with caring responsibilities' *Children and Society* 22: 253-264.

Aldridge, J, and Becker, S. (1993) *Children Who Care: Inside the world of young carers* Leicestershire: Loughborough University

Australian Bureau of Statistics (2003) *Disability, Ageing and Carers: Summary of findings* Canberra: Australian Bureau of Statistics

Australian Bureau of Statistics (2006) *Population Characteristics, Aboriginal and Torres Strait Islander Australians* 4713.0. Retrieved 28/06/2010, from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/0/1B40E5C07AF557C9CA257718002A70EC?opendocument>

Australian Bureau of Statistics (2008) *A Profile of Carers in Australia*, Australian Bureau of Statistics, Canberra, Australia.

Australian Bureau of Statistics (2009) *Carers and Employment* Australian Bureau of Statistics. Canberra, Australia.

Becker, S. (2003) 'Carers', *Research Matters* 16: 11-16.

Becker, S. (2007) 'Global Perspectives on Children's Unpaid Caregiving in the Family: Research and policy on 'young carers' in the UK, Australia, the USA and Sub-Sahara Africa' *Global Social Policy* 7:1 23-50.

Berger, K.S. (2005) *The Developing Person: Through the lifespan*, 6<sup>th</sup> edn. New York: Worth Publishers

Burnsall, S. (2003) *Understanding the Experiences and Needs of Young People Whose Parent Has an Illness or Disability*, Brisbane: Griffith University

Carers Australia (2001) *Young Carers Research Projects: Final report*, Canberra: Carers Australia

Carers Australia (2009) 'Carer Definition and Facts' Retrieved 04/08/2009, from <http://www.carersaustralia.com.au/?/national/section/16:who-we-are/0>

Cummings, R, Hughes, J, Tomy, A, Gibson, A, Woerner, J, and Lai, L. (2007) *The Wellbeing of Australians: Carer health and wellbeing* Burwood: Australian Centre on Quality of Life, Deakin University

Dearden, C, and Becker, S. (2004) *Young Carers in the UK: The 2004 report*, Leicestershire: Carers UK and The Children's Society

Duckett, S. (2000) *The Australian health care system*, 3<sup>rd</sup> edn. South Melbourne: Oxford University Press

Eagar, K, Owen, A, Williams, K, Westera, A, Marosszeky, N, England, R, and Morris, D. (2007) *Effective Caring: A synthesis of the international evidence on carer needs and interventions* Centre for Health Service Department, University of Wollongong

Gahagan, J, Loppie, C, MacLellan, M, Rehman, L, and Side, K. (2004) *Caregiver Resilience and the Quest for Balance: A report on findings from focus groups*. Nova Scotia: Atlantic Centre of Excellence in Women's Health

Heron, C. (1998) *Working with Carers*, Tyne and Wear: Athenaeum Press

Hill, T, Smyth, C, Thomson, C, and Cass, B. (2009) *Young carers: Their characteristics and geographical distribution*, Sydney: The National Youth Affairs Research Team, Social Policy Research Centre

House of Representatives (2009) *Who Cares...? Report on the inquiry into better support for carers*, Canberra: Commonwealth of Australia

Kambouris, M (2011) *Developing Health Literacy in Young Carers: A pilot project for the use of empowerment approaches*. Masters Thesis, Darwin: Charles Darwin University

Moore, T, and McArthur, M. (2007) 'We're All In It Together: Supporting young carers and their families in Australia' *Health and Social Care in the Community*, 15, 561-568.

The Carers Association of SA (2005) *Young carers: Issues affecting their education*, Goodwood: The Carers Association of SA Inc.

The Office of Standards in Education, Children's Services and Skills (2009) *Supporting Young Carers: Identifying, assessing and meeting the needs of young carers and their families*. London: The Office for Standards in Education, Children's Services and Skills. UK Government

Thomas, N, Stainton, T, Jackson, S, Cheung, W, Doubtfire, S, and Webb, A. (2003) 'Your Friends Don't Understand: Invisibility and unmet need in the lives of 'young carers' *Child and Family Social Work*, 8:35-45.

***Maria Huddleston is a Lecturer in Social Work and Community Studies, School of Health, Charles Darwin University, NT 0909, Maria.huddleston@cdu.edu.au***

***Deborah West is Associate Professor and Theme Leader of Social Work and Community Studies, School of Health, Charles Darwin University, NT 0909, Deborah.west@cdu.edu.au***