As a consequence of the deinstitutionalisation of people with disabilities and the ageing of the population in the past 25 years, the number of young people fulfilling the role of carer for a relative has increased. The difficulties faced by young carers are considerable, not the least of which is their unequal access to a satisfactory education. This paper discusses the sociopolitical, ideological and practical barriers that prevent young carers from achieving their potential in the education system, and suggests some reforms that would improve outcomes for these young people.

**Young carers and education**

**Identifying the barriers to satisfactory education for young carers**

by Tim Moore

In 1990 the Australian Government ratified the United Nation's (1989) Convention on the Rights of the Child. In signing the Convention, Australia recognised the right of every young person under the age of 18 to, among other things, a quality education (Article 28). By protecting this right, the Government made a commitment to ensuring that all barriers to access were removed so that every young Australian might fully achieve their potential (Funder 2001, p.55).

By enacting this right, the Australian Government recognised the importance of education as a major influence on a young person's learning, socialisation and their assumption of a positive place in future society (Jarmolzik & Sweeney 1996, p.150).

Education makes a significant contribution to the development and well-being of young people and their future access to employment and life opportunities (CREATE 2002, p.14).

In the year 2002 – 12 years after the Convention was ratified – Carers Australia (CA) released a scoping study of young carers in Australia. In it, the Association reported that only 4% of primary young carers aged between 15 and 25 were still at school compared to 23% of the general population. In addition, the Association reported that a majority of those not attending were doing so as a result of factors outside their control. CA (2002) writes:

> if young carers left school early it did not seem to reflect their ideals about the importance of education … it was just their only option (p.57).

Given the low rate of school attendance of primary young carers and the impact that this will have on their future lives, it is imperative that social policy-makers, educational professionals and the wider community identify and address the barriers that keep young carers in positions of disadvantage (CA 2002, p.58).

This report explores the sociopolitical, ideological and practical barriers that restrict young carers' access to and satisfactory outcomes within mainstream education.

Valuing the voices of young carers themselves, quotes from children and young people involved in the ACT Young Carers Research Project (Moore 2005a, 2005b) have been included. Copies of the ACT YCRP reports are available from the Youth Coalition of the ACT.

*Who are the young carers?*

Young carers have been defined as "children and young people who care in a family affected by the illness, disability, mental health or alcohol or other drug issue of a family member or friend" (Moore 2005a, p.65).

Primary young carers are those who are the main unpaid provider of care to a relative.

It made me gain skills – like cleaning, cooking – things you wouldn’t usually do when you were seven.

*How many young carers are there?*

It has been estimated that within Australia there are 388,800 young carers under the age of 25 (CA 2002). Of these, 18,800 identified as the main provider of care (primary carer) to their family member, and were often solely responsible for the intimate care and support of the care recipient (CA 2002, p.6).

More recent work conducted by Gays (2002) and Moore (2005a) suggests that these statistics are grossly underestimated and do not adequately account for the number of children under 15 with care responsibilities, or those caring for relatives with undiagnosed mental health or alcohol and other drug issues.

*What do they do?*

Young carers are responsible for providing health care treatment (from dressings to catheter bags), emotional support; caring for other family members; and assistance in the maintenance of a healthy, organised household. Young carers' responsibilities range from cooking through to bathing, dressing and providing assistance with toileting to incapacitated family members. Some young carers caring for a family member with a mental health condition are also required to provide other types of support, including restraint of suicidal relatives, and emotional and behavioural monitoring. A number of young carers have also reported that they have taken on the responsibility of financially providing for their families through employment or, in some cases, through illegal activity (Moore 2005a, p.29).

Often young carers take on significant caring responsibilities, such as providing primary care for a relative and/or care for multiple relatives at one time.

*Societal barriers*

In modern society, young people, as family members, have always shared responsibility for the care of relatives suffering from illness and disability (Dearden & Becker 1998). In the past 25 years, however, a number of social, political, demographic and ideological changes have compounded to increase the number of young people caring, the level of care provided, and the obstacles for these young people in accessing satisfactory outcomes in education.

... the causes of young person caring are to be found in the complex interplay between medical and social determinants, not least the "disabling" barriers engendered in much contemporary social welfare and social services policy, organisation and practice (Alldridge & Becker 1993).

**Increase in community-based care**

As a result of new technologies, the number of frail-aged, ill and disabled people in our community has risen over the past few decades. During the 20th century, for example, the percentage of persons over 65 has tripled, with the number of Australians over 80 years rising by a staggering 114% between 1971 and 1991, with projections suggesting that this increase will continue (CA 2002). At the same time, the number of people suffering from illness, disability and mental health concerns has also grown substantially (Robinson 1997, p.38).

Deinstitutionalisation and "community care"

As a result of the development of rights for people with disabilities and the aged, and running concurrently with the increase in their population, health care policies have, over the past three decades, moved towards deinstitutionalisation and the provision of community-based care – removing the sick, elderly and disabled from institutions and placing them within the community. Over this time, for example, the proportion of people with severe or profound core activity restrictions living in cared accommodation has steadily decreased from 9.9% in 1981 to 2.6% in 1998 (CA 2002, p.55). As a result, the amount and level of community care has increased, and it has been suggested that the "quality of life" of those needing care has been jeopardised by this move because inadequate resources have been provided to ensure that the carer and care recipient...
are adequately supported (Brathwaite 1990, p. 5). There has also been concern that the community care was seen as a way to curb welfare expenditure. As a result of this change, families are called upon not only to provide substantial care for relatives, but to do so with little or no resources – this situation imposes heavy restrictions on members’ access to needed supports and life opportunities.

**Changes in the family unit**

Since World War II, a number of demographic, social and economic changes have also combined to put enormous strain on families and place young people into caring roles. During this period, for example, women have returned to the workplace to maintain financial stability (Mitchell & Dowrick 1994, p.272); families have become more mobile and often move away from established familial and local support networks (de Vaus 1995, p.22); and, as a result of family breakdown and divorce (AIHW 2000, p.26), there has been a large increase in the number of single parent families.

Consequently, families called upon to care for sick, ill and disabled families are often isolated, unsupported and disconnected. Rather than relying on extended family members of the nuclear family must each take on significant care responsibilities – which often jeopardise other priorities, including education.

**Consequences for young carers**

At a result of these changes, young people are called upon to care for families who are often isolated, unsupported and disconnected. Rather than relying on extended family members of the nuclear family must each take on significant care responsibilities – which often jeopardise other priorities, including education.

**Systemic barriers to education for young carers**

There is a common and quite logical argument presented by the disability rights movement which asserts that if care is not properly resourced, the system fails to respond to a family’s situation, and to reduce a young person’s care responsibilities, it also fails to respond to the impact that caring has on young people, which is often a compromised education.

Young carers often report suffering from strain and exhaustion as a result of a heavy lifting; fatigue from working long hours; depression and anxiety, as a result of feeling hopeless and unsupported; emotional distress and psychological illness; maladaptive behaviour, as a result of traumatic and distressing situations; and an inability to concentrate while at school, as a result of feeling anxious about their relative while they are away (CA 1997, 2002; ACTYCN 2000, p.12; Ill & Northern 1990, p.72; Haber 1986, p.27).

My grades and marks were pretty crap because I was worried about getting a phone call – especially if Mum was sick ... I went to school but I couldn’t concentrate and I didn’t do well. It was all. My reports said I was a good student but that I didn’t attend enough.

At a practical level, young carers are also restricted from participating in education. Due to a lack of adequate and appropriate supports, young people’s attendance at school can be erratic (Daviden & Becker 1998, p.44) and opportunities to do homework and assignments are significantly limited (ACTYCN 2000, p.14).

Usually I’m helping out ... I have chores to do before I can do homework.

In families where a parent is the primary carer, young people are also restricted in the level of support they are able to receive. This places them in a position of disadvantage – especially as they try to catch up on missed work.

Once you’re behind its impossible to catch up (Moore 1998).

These factors combine to restrict young carers’ access to satisfactory outcomes in education and place them at-risk for early school leaving. As Webber and Hayduk report:

Home and family life play a fundamental role in the ability of a young person to successfully continue their schooling, to complete Year 10, and in the prevention of early school leaving (1995, p.6).

**Poverty and lack of financial support**

Research has shown that disability and caring are precipitous to poverty for young people, so young carers, who experience each of these phenomena, are “one of the most vulnerable and financially disadvantaged groups in Australian society” (CA 2002). With escalating costs of care (Brathwaite 1990) and inadequate financial supports (CA 1997), many young carers live in families which struggle to maintain a basic standard of living, let alone cope with rising costs associated with schooling (ACTYCN 2000; CA 2002; Moore 2005b).

Living in poverty has been identified as a risk factor for early school leaving and also for achieving satisfactory outcomes in education (ACTYCN 2000, p.4). It means there is no money for school expenses, including new text books, educational supplies and access to school camps and activities, and sets young people up for increased bullying, harassment and social isolation (Gallie 1999, p.16).

Young carers report that financial stress can significantly impact on their educational outcomes. They may be unable to afford school expenses or nutritious food, which impacts on their ability to concentrate in class. For some, this has dire outcomes:

We couldn’t buy Jacaranda (Educational Supplies), I had to steal my own books and stuff.

I didn’t go to school – I couldn’t afford the books.

**Lack of recognition**

Young carers are generally not recognised within the community. As a result, young carers are not provided with support or referred to appropriate services that may respond to their specific needs. Instead, young carers remain in a hidden group without supports or advocates.

It’s either they don’t know or they just don’t care (Moore 1998).

Young carers remain hidden for a number of reasons. First, parents are often concerned that they will be deemed unfit or inadequate if their child’s caring responsibilities are known (Keith & Morris 1995, p.43). This fear is commonly expressed by people involved in the disability movement – many concerned that “the identification of children as carers has far-reaching, and potentially devastating consequences for many disabled and/or ill parents” (Keith & Morris 1995, p.55).

I don’t deserve for people to do stuff for me. Mum’s the one who’s had to go through so much. She’s the one that people should be helping. Not me (Moore 1998).

Second, many families and young carers believe that caring should be a private matter:

... the embarrassment and shame often associated with having a child with a disability, may inhibit some carers from seeking assistance at all (Department of Human Services and Health (HACC Division) 1996, p.2).

Third, and most commonly, the reason young carers remain hidden is fear of being separated from their families by child protection authorities. Keith and Morris (1995, p.43) argue that this fear is not unfounded, with many children taken into care as a result of a “prejudicial treatment from child protection agencies and courts” against families affected by illness or disability. Realising this, many families feel compelled to hide the responsibilities of their children to maintain family togetherness.

We didn’t want people to know in case they thought dad wasn’t looking after me properly. I mean he was, but we were scared that because he was in a wheelchair they’d take me away (Steven, 14 years).

**Services which are aware of young carers’ needs often do not feel adequately skilled or resourced to work with the myriad and complex issues that young people face.**

At the same time, recent studies have found that services which are aware of young carers often do not feel adequately skilled or resourced to work with the myriad and complex issues that young people face and therefore do not actively engage or work with this group. As Gays (1998) puts it, “we don’t know how to treat them so we largely ignore them”.

For political and ideological reasons, policy-makers have also failed to acknowledge and respond to the existence of young carers. On one hand, young carers are providing an invaluable service to the community (actively contributing to annual savings for the Commonwealth Government of over $18 billion dollars), but, on the other hand, they are missing out on education, social participation and other mainstream life opportunities.

**Within the school gates**

While there are a number of external systemic barriers to young carers achieving satisfactory outcomes, there are also significant hurdles that must be overcome within the school gates. The lack of awareness of the existence of young carers and the impact of caring, and a lack of appropriate responses, mean many young carers are unable to navigate their way successfully through their schooling years. When these
In a appropriate lives (ACTYCN 1997, 2000, p.3; CA 1997): I write a story about being a young carer but my teacher said it was a load of crap. That got me cut.

There was this one teacher who made me stand up in front of the class and asked me why I hadn't done my homework. I told her my mum was sick and I had to care for her. She said that everyone has to do jobs at home but they still had time to do homework. She said I have to look after my husband and clean the house – you don’t see me using it as an excuse... That made me go off. I said “Listen here, you bitch, my Mum is dying and I have to do everything for her. You don't know what it's like. I've seen you sitting around at the shops on your fat big arse drinking coffee – don't tell me you know what it's like because I never have any time to sit around with you. Don't tell me you don't know nothing...” I got suspended and my Mum had to threaten the principal to let me come back to school. My school refused to help her (the teacher) – it's just not fair.

Inappropriate responses

While a lack of awareness is difficult, so is the inappropriate use of information by educational professionals. For example, a young carer reported that when she told one of her teachers that her mother had been admitted to hospital after a suicide attempt, he responded by giving her extra homework “to take her mind off her situation”. Other research has found that teachers sometimes “collude” with parents and others by encouraging young people to miss school to care for their relative (Dearden & Becker 1998, p.44). Though well-intentioned, these actions heighten young carers’ anxiety and pressures and makes it even more difficult to achieve at school.

Anti-disability culture

Though often aware of the existence of young carers in school, teachers and other students often tolerate and sometimes encourage a school culture with an anti-disability and mental health focus, which discourages young people from identifying as carers and seeking support.

The teachers let the other kids pick on people with disabilities, which made it hard to talk about.

Some teachers talk about "spastics" and "retard", if so they do it, how's things gonna change? I told one teacher and she said that I was being over-sensitive and that I shouldn't go "schizo"... She said that.

As a result, young carers whose lives focus around illness and disability feel attacked (and often bullied) and ostracised from the wider school community. They lack a sense of belonging, which has been identified as a necessity for student achievement (Webber & Hayduk 1995). The ACT Young Carers Network found that “...the lack of support and stigma that a young carer faces at school makes them disillusioned and unwilling to participate in education” (2000, p.5). The Princess Royal Trust for Carers found that 71% of young carers had been bullied and that this had led to 20% of them not attending school (Cubitt & Warner 1999).

Lack of relevance

It has been shown that relevance is an important factor in a young person's access to and achievement in education (see 1991, p.24). To fully address this need, it is suggested, the curriculum should be relevant and, where possible, reflect and have practical implications for the lives of students. (See 1991, for example, suggests that schools with high drop-out rates “do not, through their curricula, establish a climate of acceptance of students in different or difficult circumstances [and that their] social ostracism leads to many feeling little option but to leave school” (p.25).

In 2001, the ACT Legislative Assembly found that, there is a general perception that mainstream (schools) ... only cater for the ‘average young person’ and do not have flexibility to meet the needs of students outside the norm (p.21).

As a group whose life experiences are far from average, young carers are thus disadvantaged within the current system.

Inflexibility of delivery

It has also been argued that to fully encourage and allow access to at-risk young people, schools must be flexible in their delivery of education (CREATE 2002, p.58). This is particularly important for young carers whose care responsibilities do not always allow them to participate between the hours of nine and three (ACTYCN 2000, p.8). Rigorous and set expectations of these systemic, ideological, practical and pressures and makes it even more difficult to achieve at school.

Other research has found that people from identifying as carers and disabilities, which made it difficult for young people not achieving satisfactory outcomes in education. Though to discuss in detail is outside the parameters of this report, it is argued that significant, measurable and proactive steps must be taken to reduce these barriers if Australia is going to support its own every young person’s right to an education. We want to learn. But we can’t. Please help us (Moore 1998).

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