# Evidence Brief:
# Understanding the Needs of Young Carers

This paper was commissioned by the Ministry of Social Development, Wellington, New Zealand, 2014. The views and interpretations expressed in the paper are those of the researcher and are not an official position of the Ministry of Social Development.

**Key Points**

- For the purposes of this brief, a young carer is a child or youth aged up to 25 years who provides significant, ongoing support for someone with a disability, health condition, injury, addiction, or who is an older person requiring assistance with everyday living.

New Zealand:

- The latest New Zealand Census reveals 40,000 18-24 year olds have a care role (Statistics New Zealand, 2014a). Because Census data only recognises carers over the age of 15, it is possible that many young carers are missing from the Census statistics.
- There is minimal literature on young carers in New Zealand. Only four studies of New Zealand young carers have been found.
- Māori and Pasifika people are more likely to choose family/whānau care, and less likely to access formal supports and services. One reason is the lack of culturally appropriate services for people requiring care.
- Themes established in the international Western literature are relevant to New Zealand.

Internationally:

- No consistent and agreed-upon age-range for a *young carer* is universally applied in research.
- Young carers are more likely to be school-aged, the oldest child, and living in a low socio-economic household; they are marginally more likely to be female, and may begin their care role at a very young age. An Australian study found that for young carers who were the primary caregivers, two thirds were females.
- Young carers are most likely caring for someone with a disability or mental illness, most likely their mother.
- A key factor that appears to lead to children and youth taking on a carer role is inadequate, insufficient, or culturally insensitive services for the person requiring care.
- Positive outcomes for young carers include their desire to carry out their care roles, the formation of lifelong memories and familial bonds, and gaining a sense of self-respect.
- Negative impacts for young carers include reduced social networks, lower educational achievement, greater unemployment, and the family's choices not to engage with social services due to parental fear of child removal or familial disjunction.
- Newman (2002) argues that claims made regarding negative outcomes for young carers have no direct relationship to the illness or impairment of the care recipient and instead "are frequently related to poverty, social exclusion, and unsupported or inadequate parenting" (p.613), and the lack of support available to assist.
- However, Cooklin (2010) found that children and young people caring for someone with a mental illness, in particular, were vulnerable to several negative emotional impacts.

- The hidden or invisible nature of young carers creates significant challenges for identification worldwide.
- The need for more research is a strong theme across the literature.

Recommended key areas of focus:

- Focus on low socio-economic households may need to be a priority, as access to and communication about services is traditionally more limited for families living in areas with higher levels of poverty.
- Perceptions of caring, health, and disability are culture-bound. Approaches to supporting young carers that are responsive to the needs of different cultural groups – for example, Māori and Pacific young carers – may be needed in New Zealand.
- Conversations around services for young carers will need to focus on the care needs of the young carer and their care recipient, and take into consideration the wider household context, in order to cater effectively to the specific needs of individual young carers.
- Young carers in New Zealand need more opportunities to access and build informal support networks. Respite or other services for young carers are also important to ensure they have the time to develop and maintain friendships both at school and in their community.
- Key service provisions for young carers include age-appropriate information pertaining to the disability or health condition of the care recipient and the supports available to them, and innovative supports utilising technology and popular media. There is a need for a conversation around ways to best utilise web-based, mobile, and social media technologies to engage a widespread group of largely unrecognised young carers.
- What doesn't work?
  - providing information without widely advertising its existence and availability.
  - information in hard copy forms only (eg brochures), disregarding social media forms.
  - information created without young carer consultation on what they need and what is appealing.
  - information provided that does not reflect the cultural contexts of young carers.
- According to the Disabilities and Carers Collective (2006), workers in the disability, welfare, health, or education fields are often unaware of how to identify or support young carers. In particular, information needs to be provided to teachers at all levels of education. The Young Carer Bursary Programme is a new initiative by Carers Australia, aimed at helping young carers to combine education with their caring responsibilities.

# Overview

While care[1] provision is often seen as a natural family function, the young carer subgroup is considered in the literature to be a hidden carer population facing adverse outcomes. For the purpose of this evidence brief, young carers are youth aged up to 25 years providing significant, ongoing support for someone with a disability[2], health condition, or who is an older person requiring assistance with everyday living. Because of their age, young carers face unique vulnerabilities that distinguish their needs from the general carer populace (Noble-Carr, 2002). In the UK and Australia, considerable research has been conducted specifically on young caring. In New Zealand, a small body of literature has resulted in little being understood about New Zealand young carers. Themes established in the international Western literature are relevant to New Zealand.

Existing international and national research offers information about young carers, including that they are:

- often school-aged (eg Lackey & Gates, 2001)
- marginally more likely to be female than male (eg Shifren & Kachorek, 2003)
- caring across diverse cultures and ethnicities (eg Sahoo & Suar, 2009, 2010)
- commonly residing in sole-parent families (eg Dearden & Becker, 2004)
- frequently from low socio-economic households (eg Aldridge & Becker, 2003).

Young carers are likely to be:

- providing care for their mothers (eg Noble-Carr, 2002), or for someone with a disability or mental illness (eg Collings & Llewellyn, 2012)
- gradually socialised into the caring role (eg Banks et al., 2002)
- delivering a significant or substantial level of care (eg O'Dell, Crafter, De Abreu, & Cline, 2010).

Literature points to young carers' invisibility throughout society, and policy and services implementations (eg Kennan, Fives, & Canavan, 2012). The reason for their invisibility may be people's disassociation of children and primary caring roles, making them "unaware that young carers exist" (Waugh, Szafran, Duerksen, & Torti, 2012, p. 3). The need for more research is a strong theme across the literature (eg O'Connell, Finnerty, & Egan, 2008).

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[1] A carer is anyone providing support for someone close to him or her who requires care due to a disability, health condition, injury or addiction (Ministry of Social Development [MSD], 2008).

[2] The use of person-first language used throughout the evidence brief aligns with American Psychological Association (APA, 2014) stipulations for non-handicapping language putting the person before the disability or illness, eg person with a disability.

This evidence brief identifies the information needs of New Zealand's young carers. In order to examine their information needs, we first need to understand as much as possible about the experiences and challenges that young carers face in their caring roles, and from there we can effectively develop resources to support their wellbeing. Due to a lack of New Zealand research, this evidence brief draws on data from a range of New Zealand reports and sources that help paint a picture of young carers' prevalence, experiences, and needs, which is integrated with the much larger body of international research on young caring. The evidence brief examines how knowledge from international research can inform the kinds of information we offer in New Zealand if we are to appropriately support young carers.

## New Zealand young caring context

New Zealand, like many countries, has a population of young carers. However, extensive examination of New Zealand literature found just four published studies, (Ferguson et al., 2001; Gaffney, 2007, 2009; McDonald, et al., 2009), all of which cite the need for further research. Gaffney's (2007) New Zealand study outlines young caring as an "area of concern" requiring further research (p. 7), and is supported by McDonald et al.'s (2009) New Zealand study, which concludes; "further qualitative research with a broader range of young carers and their families will increase our understanding of their lives and experiences" (p. 126). Lacking in current New Zealand research are studies examining the information needs of young carers.

The Ministry of Social Development holds information on carers who receive the Supported Living Payment benefit (SLP)[3]. This client database has the potential to provide a profile of carers receiving the SLP by age (from 17 years), gender, income and ethnicity.

## Defining 'young carer'

No consistent and agreed-upon definition of *young carer* is universally applied in research. In particular, the age range that includes young carers differs by up to eight years. For instance, Smyth et al. (2011) define young carers as "young people up to the age of 25" (p. 145), whereas Gaffney's (2007) definition is "children up to 17 years" (p. 5). Although the average age of young carers is 10-13 years (eg Dearden & Becker, 1998; Lackey & Gates, 2001), studies in the USA, Scotland, Australia and Kenya found that caring roles can begin from as early as three, four or six years old (Andersen, 2012; Barry, 2011; Lackey & Gates, 2001; Noble-Carr, 2002).

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[3] The Supported Living Payment helps people who are caring full time at home for a person who has a serious health condition or disability and who needs full time care, is not the carer's partner or spouse, and would otherwise need hospital care, rest home care, residential disability care, extended care services for children and young people with severe disabilities, or care of a similar kind.

The general consensus for the age at which young caring finishes, as the child or young person graduates to being an adult carer, is 17 to 18 years (Becker, 2007; Cree, 2003; Eley, 2004), although several researchers include the transition to adulthood and extend the parameters to include carers aged up to 25 years (Butler & Astbury, 2005; Dearden & Becker, 2004; Levine et al. 2005).

The absence of a uniform definition makes direct comparisons across studies difficult, especially when speaking to young carers' prevalence in a given population. Accordingly, focus is on the broad similarities across studies, and prevalence data is grouped only when researchers' definitions align. The definition of young carer used in this evidence brief is a synthesis of those used in the literature. It is broad enough to incorporate the widest range possible of New Zealand's young carer population – that is, children and youth aged up to 25 years who provide significant, ongoing support for someone with a disability, illness, or who is an older person in need of support.

## Profile of Young Carers

### Activities/tasks

While there is no shared definition of young carers, authors agree that a key factor distinguishing young carers' roles is the significant or substantial level of tasks (Andreouli, Skovdal, & Campbell, 2013; Cooklin, 2010; Gray, Robinson, & Seddon, 2008; Thomas et al., 2003). Several authors stress the adult-like nature of young carers' tasks (Aldridge & Becker, 1993; Becker, Dearden, & Aldridge, 2000; Noble-Carr, 2002). Becker et al. (2000) state, "in many families, children are involved in exactly the same types of care work as other (unpaid) adult carers" (p. 6). Key among the wide array of care tasks are:

- domestic responsibilities such as household chores and shopping
- emotional support including companionship and supervision
- intimate care comprising bathing, dressing, and toileting (Banks et al., 2001; Hunt, Levine, & Naiditch, 2005; Lackey & Gates, 2001).

The level, duration, and nature of tasks are largely influenced by the care recipient's disability or illness. Dearden and Becker (2004) reported that individuals with a physical disability more commonly require intimate care, whereas care recipients with a mental illness most often require emotional support. The range of intensity of care roles differs depending on the care need. Young caring due to drug or alcohol dependency may include ensuring care recipient safety, looking after or protecting siblings, and providing significant emotional support, on top of practical tasks such as household chores and personal care (Frank & McClarnon, 2008). Young caring due to mental illness often means the care role fluctuates in intensity, with secure periods followed by "periods of instability, confusion and emotional upheaval" (Frank & McClarnon, 2008, p. 7). Young carers of care recipients with AIDS/HIV may feel even more hesitant to disclose their care roles due to the stigma attached to the illness, or may experience withholding of information to the young carer about the true diagnosis (Frank & McClarnon, 2008).

Certain disabilities and illnesses require young carers' roles to extend into adulthood, whereas others have a shorter care-need lifespan (eg terminal illness), and in both situations, care needs can be episodic (Aldridge & Becker, 2003; Ferguson et al., 2001). While limited data exists concerning the length of time spent caring, the Australian Government commissioned Occasional Paper No. 47 (Bray, 2012) on young carers found that duration of caring was fairly long for young carers, with 75 percent still caring 47 weeks after beginning care, and 50 percent after 141 weeks.

## Prevalence

### England and Wales

According to the Office for National Statistics' (ONS, 2014) a young carer is anyone aged 5-17 years providing some level of unpaid care. ONS (2014) latest Census data states that in 2011, there were 177,918 young carers in England and Wales – 2.1 percent of the total population of 5-17 year-olds in that region. An increase in the number of young carers was seen in all regions of England and Wales between 2001 and 2011. However, the Children's Society (2013) reports this is likely to be an under-representation of the true number, as many young carers remain hidden to professionals. Supporting this, a 2010 BBC and University of Nottingham survey states that the number given for young carers is a significant under-representation of the true number, and estimates that there are 700,000 young carers in the UK.

### Australia

Australian prevalence data comes from the 2012 Survey of Disability, Ageing and Carers (SDAC), conducted by the Australian Bureau of Statistics (ABS) from August 2012 to March 2013. The definition of care guiding this survey was "a person providing any informal assistance to someone who has a disability, long-term illness, or who is elderly, usually for at least six months." The survey identified 2.7 million unpaid carers in Australia, of which 300,000 (11 percent) are young carers aged 25 years and under (ABS, 2012). Of the 300,000 young carers, almost 75,000 (25 percent) were aged less than 15 years.

### New Zealand

In New Zealand no data exists specifically addressing the prevalence of young carers. However, the latest New Zealand Census reveals 40,000 18-24 year olds have a care role (Statistics New Zealand, 2014a). A review of the 2006 Census data (Statistics New Zealand, 2007) reveals that approximately 20 percent of 15 to 24 year olds reported caring for a family member(s) with a disability or illness. These Census statistics need to be taken with caution, however, as the Census caring question only asked about care tasks carried out in the four weeks prior to the Census (Statistics New Zealand), so anyone who cared for a family member with a short-term illness, such as the flu, in the four weeks prior to the Census is consequently acknowledged as a carer.

Furthermore, because the Census data only recognises carers over the age of 15, it is possible that many young carers are missing from the Census statistics. Key UK young carer researcher Professor Saul Becker states, "because young carers have been a 'hidden' group in all countries, reliable and comparative indicators of the extent of children's caring roles are seriously underdeveloped" (2007, p. 26). This is certainly true in the New Zealand context.

## Gender

Generally, females are more likely to be young carers than males, albeit by a small margin (Banks et al., 2002; Butler & Astbury, 2005; Eley, 2004; Levine et al., 2005; Noble- Carr, 2002). Of the 177,918 young carers aged 5-17 years identified in the latest UK Census data, 54 percent were girls and 46 percent were boys. Orsmond and Mailick Seltzer's (2000) longitudinal, quantitative study of siblings in care roles found that sisters were slightly more likely to be young carers than their brothers, although the authors note that other factors influence adoption of the role, such as physical proximity and sibling psychological-wellbeing.

The Young Carers Research Project: Final Report published by Carers Australia (2002) found females were only slightly more likely to become young carers than males. However, for young carers who were the primary caregivers, two thirds were females. Several studies also found that the prevalence of female young carers is substantial in comparison to males, although they did not distinguish between primary and other young carers (Lackey & Gates, 2001; Shifren & Kachorek, 2003).

## Culture/ethnicity

Andersen (2012) points out that although the family unit is the focus of caring in almost all societies, the kind of caring activities expected is "specifically and culturally defined and varies between contexts" (p. 206). Situating young carers in their cultural context is critical, as the status of caring and the way it is understood will vary both within and across nations, influencing the implementation and delivery of services for young carers and their families. Frank and McClarnon (2008) point out that UK young carers from Black, Minority and Ethnic (BME) communities, and those for whom English is an additional language, may:

- struggle to understand information about services
- experience racial discrimination on top of discrimination about the care recipients' disability or illness.

In collective cultures, caring for a sick or disabled family member is likely to be seen as the role of the family, and formal services may not be sought as freely as in an individualist culture, where the care responsibility may be more likely to be given to a service provider. For example, in India, families' preferences for young carers over outside help is understood as a sign of children's respect for their elders, and as a means of retaining "strong emotional bonds" within the family (Sahoo & Suar, 2010, p. 324).

Numerous collective cultures – such as Pacific and Māori families – are providing care within individualist societies such as New Zealand. Collins and Willson (2008) stress that whānau is at the heart of caregiving relationships for Māori families, who often have a strong preference for whānau support over formal support systems. The notion of whānau carers is wider than the nuclear family, and includes "kin, as in whakapapa whānau, or people with a family-like commitment to a common interest, as in kaupapa whānau" (Collins & Willson, 2008, p. 5). Whānau carers also extend to young whānau, with Māori participants in Nikora, Karapu, Hickey, and Te Awekotuku's (2004) report thinking it common for young children to provide care for a parent with a disability when the child demonstrated the aptitude or conditions became desperate. As such, Māori families may feel tension with the individualist stance on care dominant in New Zealand.

While there are hints of the cultural context of caring in existing literature, research largely addresses European carers in Western nations. Approaches to supporting young carers that are responsive to the needs of different cultural groups – for example, Māori and Pacific young carers – may be needed in New Zealand.

## Characteristics of young carers' wider household contexts

Children are more likely to take on a care role if they are the eldest in their family or are residing in a sole-parent family (Andersen, 2012; Barry, 2011; Dearden & Becker, 2004; Hunt et al., 2005). According to Noble-Carr (2002) the sole-parent family dynamic can bring about a dearth of carers in the household, resulting in young carers filling the void. Noble-Carr projects rising numbers of Australian young carers, as a 30-year growth of sole-parent households continues (Australian Institute of Family Studies, 2014).

Likewise, in New Zealand, sole-parent households are projected to increase at an annual rate of 2 percent, from 363,000 in 2006 to 602,000 in 2031 (Statistics New Zealand, 2010). Although a significant group of young carers are in sole-parent families, even where there are two parents, the non-affected parent may reject the carer role (Abraham & Aldridge, 2010; Aldridge & Becker, 1993). Nevertheless, consideration of household structure and family system will be key in identifying the information needs of young carers and their families, and implementing services for them.

Low socio-economic status could be a key factor mediating the onset of care by children (Aldridge & Becker, 2003; Becker et al., 2000; Dearden & Becker, 2000; Hunt et al., 2005). Bray's (2012) Australian report on young carers found they "were nine times more likely to be living in areas of high socio-economic disadvantage" (p. viii).

Ferguson et al. (2001) noted that a common factor among New Zealand young carers identified by service agencies was low socio-economic background, although it was not clear if their low-income status was the result of disability or illness in the family. Greater instances of low socio-economic status for families with young carers could be possible, since disability and illness are strongly connected with negative changes in families' financial situations, especially if the person who has become disabled or ill is the breadwinner (Lackey & Gates, 2001). Focus on low socio-economic households may need to be a priority, as access to and communication about services is traditionally more limited for families living in areas with higher levels of poverty.

## What are the barriers to identifying young carers?

### The hidden nature of young caring

Before young carers can be supported, they must first be identified. Identification poses a significant challenge in all parts of the world. The hidden or invisible nature of young carers is widely cited throughout the literature (Banks et al. 2002; Becker, 2007; Gray et al., 2008; Skovdal & Mwasiaji, 2011; Smyth et al., 2011; Thomas et al., 2003). Waugh et al. (2012) believe the reason for their invisibility is societies' oversight of children in primary caring roles. Aldridge and Becker (2003) believe that young carers' roles are not only concealed from the public but "can also be hidden from children themselves" (p. 56).

Indeed it appears that many young carers are neither aware of nor identify with this label (Kennan et al., 2012; Smyth et al., 2011). Lackey and Gates (2001) point out that the invisibility extends to former young carers, with several participants in their study not identifying or recognising themselves as having been young carers until they were asked to participate in the research. If information provision and services are to address young carers' needs, they must, in the first instance, identify young carers who may be hidden even to themselves.

### Young carers' fear of bullying

The Western literature identifies fear of being teased as a key reason for young carers' reluctance to draw attention to their caring roles (Banks et al., 2002; Cree, 2003; Princess Royal Trust, 1999). For example, in the UK, over a quarter of surveyed young carers did not tell their friends that they were providing care for another person because they feared being teased or alienated by their friends (Princess Royal Trust, 1999). Respecting parental requests for privacy is demonstrated by a 12-year-old girl who said, "sometimes when I go to school with my pals they say what's the matter? … and I just say, nothing, just leave me", and a 13-year old boy who stated, "me and my Dad always kept the family business in the family. Didn't go any further than us and that was it" (Banks et al., 2002, p. 240). Barry (2011) found Scottish young carers "tended to feel more protective of their families" (p. 528) so requests by care recipients to keep their role secret would be strictly adhered to.

According to the Association of New Zealand Advertisers (ANZA, 2014), "public service advertising has proven to be an effective way to address societal challenges" in New Zealand, for instance in de-stigmatising depression, fighting domestic violence, and generating awareness of breast and prostate cancer. In particular, the "Blazed – Drug-Driving in Aotearoa" and "Legend" (aka "Ghost Chips") public service advertisements became popular culture classics, and created a space for youth to talk about drug- and drink-driving with their friends.

In light of young carers' hesitation to be identified due to fears of bullying, public service advertisements that discuss young caring with a touch of humour and identify the positive aspects of young caring, while also highlighting the struggles, could increase awareness and understanding of young carers' roles. They may assist in encouraging young carers to self-identify and access services for themselves and their family.

## Parental fear of child removal

Thomas et al. (2003) point out another key reason why young carers and their families might choose not to disclose young caring roles is parental fear of child removal or familial disjunction. According to Keith and Morris (1995), this fear may not be unwarranted, as child removal of young carers is not uncommon. In fact, parental disability or ill health has been cited as the third most common reason for children being admitted to state care in England (Dearden & Becker, 2005).

McConnell and Llewellyn (2002) found that in research samples of parents with intellectual disabilities – including samples from the US, Australia, Canada, the UK, and other countries – investigators consistently found that between 40-60 percent of the children had been removed. Emerson, Malam, Davies, and Spencer (2005) reported that, of almost 3,000 surveyed adults with learning disabilities, 48 percent were not in custody of their children. However, neither of the latter studies examined the reasons behind children not living with their parents; therefore we cannot assume they were taken into care or removed because of their parents' disability. Furthermore, numerous other studies suggest that children may be taken into care not because of their parents' disability, but because of unwarranted assumptions made about the parents' disability, including the assumption that their children will be young carers (eg IASSID, 2008).

A review of the UK child protection literature revealed that a "significant proportion" of children in the child protection system were from families in which the parent had a mental illness or substance dependence (Cleaver, Unell, & Aldgate, 1999, p. 13). Another study, of young carers of parents with a mental illness, revealed an apparent connection between parental mental illness and child safety concerns, as demonstrated in one parent's statement, "I was frightened [of contacting a young carers project], you know, because I imagined them taking me kids off me for the way I was and things like that… so instead of bringing help in I was pushing them all away because I was too frightened of it" (Aldridge & Becker, 2003, p. 49). As this parent's testimony illustrates, parents can experience heightened anxieties from an overriding concern about their child being removed.

Cleaver and Nicholson (2007) stress that for services to be accessed, "practitioners must develop open, honest and cooperative working relationships with parents ... [to] encourage them to feel confident in providing vital information about their child, themselves and their circumstances" (p. 105).

While New Zealand data concerning removal of children due to parental disability is limited, a New Zealand Families Commission study (Kerslake Hendricks & Stevens, 2014) identified that a parent with an intellectual disability was one of two key groups for notifications of vulnerable infants. Key issues identified in the report that possibly underline over-representation are:

- social isolation, poverty, and poor health – all of which are linked to a greater risk of child abuse and neglect – due to parental intellectual disability
- incorrect beliefs about parents with an intellectual disability's ability to provide care (Kerslake Hendricks & Stevens, 2014).

It appears parental fear of child removal or familial disjunction in New Zealand may be justified, due to circumstances related to being a person with a disability, rather than ability to care for a child.

## Whom do young carers care for?

Although young carers support a range of care recipients with diverse needs, parents, in particular mothers, appear to be the most common care recipients in Western nations (Abraham & Aldridge, 2010; Becker et al., 2000; Cooklin, 2010; Cree, 2003; Williams, 2012). In Noble-Carr's (2002) Australian study, over half the young carers were caring for a parent, and most commonly their mothers. In New Zealand, Ferguson et al.'s (2001) study found most of the young carers identified by community social support agencies were caring for parents. New Zealand data show children aged 15 and over providing care for their parent(s) is the second most common form of non-agency delivered care provided to persons with a disability or illness (Office for Disability Issues, 2009). An estimated 12,100 and 9,500 New Zealand adults with a disability get help every day from their daughters and sons respectively (Office for Disability Issues, 2009).

People with a physical disability are the most common care recipients looked after by young carers (eg Ferguson et al., 2001; Noble-Carr, 2002), followed by people with a mental illness (eg Aldridge, 2006; Cooklin, 2010). Additionally, young carers are cited as caring for people with specific illnesses such as: HIV/AIDS (eg Robson, Ansell, Huber, Gould, & van Blerk, 2006; Tisdall, Kay, Cree, & Wallace, 2004); cancer (eg Gates & Lackey, 1998); dementia/Alzheimers (Lockeridge & Simpson, 2012; Svanberg, Stott, & Spector, 2010), and substance abuse (Moore, McArthur, & Noble-Carr, 2011; Templeton, 2012). Dearden and Becker (1998) found 63 percent of young carers in their UK study cared for someone with a physical disability. Similarly, Carers Australia (Noble-Carr, 2002) found the care recipient was often someone with a physical disability, followed thereafter by a person with a mental illness.

It is interesting to note that there could be a significant number of New Zealand young carers looking after elderly family members, due to the trend of grandparents taking on parental roles. The latest Health 2000 survey found grandparents were important caregivers, particularly for students residing in more deprived New Zealand neighbourhoods (Clark et al., 2013). Supporting this, the latest New Zealand Census reports that 9,500 grandparents are in a parental role to their grandchildren (Statistics New Zealand, 2013). Children being cared for by their grandparents could, in turn, become the carer as their grandparents become unable to cope.

## Barriers to services for young carers and their care recipient

The nature of the care recipients' disability or illness may impact how and whether a young carer gains access to services. For instance, carers of individuals whose illness is episodic may face additional barriers. Ferguson et al.'s (2001) New Zealand young carer study found "many agencies identify mental health issues and drug abuse as an area of major concern that requires attention" (p. 17). However, services often overlook young carers of people with a mental illness.

Despite not specifically pertaining to young carers, Boyd and Sigglekow's (2011) New Zealand study on mental illness found in some cases young children became their parents' primary carers at an age when support was still needed by the children themselves. In light of the Mental Health Commission and KITES' (2005) finding that 50 percent of persons with a mental illness are parents, the prevalence of young carers of parents with mental illness could be significant. This is not to suggest that all children with family members or friends with a disability, poor health, or mental illness will become young carers (Aldridge & Becker, 2003). However, it appears from the literature that while young carers look after people with a range of care needs, people with a disability or mental illness most commonly receive their care.

Nevertheless, Newman (2002) points out that claims made regarding negative outcomes for young carers "have no direct relationship to illness or impairment" and instead "are frequently related to poverty, social exclusion, and unsupported or inadequate parenting" (p. 613). As such, conversations around services for young carers will need to focus on the care needs of the young carer and their care recipient, and take into consideration the wider household context, in order to effectively cater to the specific needs of individual young carers.

## What are the factors influencing young carers taking on their care role?

### Lack of support for the person requiring care

A key factor that appears to lead to children and youth taking on a carer role is inadequate, insufficient, or culturally insensitive services for the person requiring care (Becker, 2007; Eley, 2004; Gaffney, 2007; Smyth et al., 2011; Williams, 2012).

Interviews with seven New Zealand families with young carers revealed several barriers to services, including high costs, being unaware of what was available, or being prescribed unacceptable or rigid services that did not truly address the family's needs, leaving families with the choice to settle for what they were given, fight for better services, or pay more to access required support (McDonald et al., 2009).

Keith and Morris (1996) asserted that the absence of adequate support services restricts what people with disabilities can do for themselves, and creates a role for other family members to assist them. As such, it is not the disability or illness alone, but the lack of support available to assist.

In particular, mental illness may be a key area with a lack of support, as the stigma attached may mean families become isolated and prefer to keep caring within the family unit, not because it is the best option but because it avoids shame and embarrassment (Cooklin, 2010). In addition, families with mental illness often have lower standards of living and face financial hardship (Cooklin, 2010). A significant group of New Zealand young carers may, therefore, be filling the gap, and this could be particularly the case for cultures whose interpretations of mental illness mean the family is unable to understand or unwilling to accept the illness (Frank and McClarnon, 2008).

Services for older people is another key area, as an ageing population demands more carers. Statistics New Zealand (2014b) projects that by 2032, 21–22 percent of New Zealanders will be aged 65+, compared with 14 percent in 2014. By 2050, this proportion is expected to reach 22–26 percent, and reach 24–32 percent by 2068. Within the 65+ age group, the number of people aged 85 and over (85+) is expected to increase significantly, from 78,000 in 2014, to 220,000–270,000 in 2041, and 320,000–450,000 in 2068. By the 2050s, about one in four people aged 65+ will be 85+, compared with one in eight in 2014.

Additionally, the longer life-span of people with disabilities and the increasing prevalence of illnesses such as diabetes and cancer, will place significant pressure on health care provision, and is likely to result in increasing numbers of the population requiring care.

A UK report by Frank, Tatum and Tucker (1999) strongly states that national or other welfare agencies should not overlook the on-going welfare needs of young carers. Instead, policy and practice should be developed by the state based on the United Nations Convention on the Rights of the Child 'participation', 'protection', and 'provision' clauses (Frank, Tatum, & Tucker, 1999).

In line with this, a report by Noble-Carr (2002) for Carers Australia states the government is responsible for adequate service provision for young carers, and "this is due to the fact that young carers provide for ill and disabled people, and this has been quoted as saving the government an enormous amount of money" (Noble-Carr, 2002, p. 17). In New Zealand the value of "informal" care is NZ$10 billion per year (Grimmond, 2014), yet families with "informal" carers have on average 10 percent less income than families without (Statistics New Zealand, 2014a).

### Lack of culturally appropriate services for the person requiring care

In New Zealand, the Office for Disability Issues (2009) found young caring among Pasifika and Māori populations, with Pacific adults being the most likely to receive support from "informal" carers (37 percent). This was followed by Māori and European adults (both 25 percent).

Perceptions of caring, health and disability are culture-bound. Māori and Pasifika people are more likely to choose family/whānau care, and less likely to access formal supports and services. Outside of cultural preferences, a possible explanation for the high instances of "informal" caring amongst Pasifika families is a lack of culturally appropriate services and inadequate use of Pacific languages by service providers (Office for Disability Issues, 2010). Culturally insensitive service delivery may be occurring in the 22 Pacific communities in New Zealand, "each with its own distinctive culture, language, history, and health status" (Ministry of Health [MoH], 2008, p. 7).

Similarly, in the case of Māori carers, both the Ministry of Health (2009) and Wiley (2007) found dissatisfaction and disappointment with culturally insensitive services. As a result, Māori with a disability or health condition may choose family/whānau carers over accessing culturally insensitive services, and this in turn may suggest a population of Māori young carers. There is an apparent need for further research with participants from a mix of New Zealand environments (rural, urban) and regions and representing a diversity of ethnicities (Lackey & Gates, 2001; Marote et al., 2012; Sahoo & Suar, 2009, 2010), especially as the 2013 Census results show an increasingly ethnically diverse New Zealand population (Statistics New Zealand, 2013).

## What are the impacts of caring during childhood for young carers?

Young carers experience a range of emotional, social, educational, and health impacts stemming from their caring roles. The majority of the research has focused on negative outcomes, including guilt and anger, missing school, and lower levels of both educational achievement and employment. However, there is also evidence of positive outcomes related to familial bonding and self-respect that need to be considered.

## Adverse emotional implications

Numerous studies suggest negative emotional implications for young carers, including unresolved distress, anxiety, grief, anger, and guilt (Barry, 2011; Cree, 2003; Dearden & Becker, 2005). Noble-Carr (2002) proposes that, in the long term, negative feelings could contribute to depression and emotional breakdowns, a proposal that is supported by Becker et al.'s (2000) assertion that young carers' adult-like roles "have a negative impact or outcome for their own well-being and psycho-social development and transition from childhood to adulthood" (p. 2). A large UK study found that young carers were "significantly more depressed, and had lower self-esteem than non-carers" (Banks et al., 2002, p. 237). Similarly, while not specifically pertaining to young carers, a study of the wellbeing of Australian "informal" carers found carers' wellbeing was the lowest of any group in Australia (Cummins et al., 2007).

Fergusson et al.'s (2001) New Zealand study also raises the notion of young carers "parenting the parent", stating the serious implications this can have for children in terms of missing out on being a child due to their significant parental role at a very young age (p. 18). With emotional wellbeing being a key component of students' ability to cope with school and to contribute to their families, services addressing young carers' mental and emotional health needs during and after their young caring roles are important (Crengle et al., 2013).

Cooklin (2010) found that children and young people caring for someone with a mental illness in particular highlighted negative emotional impacts including:

- invasion of their thinking and feelings due to exposure to care recipient's delusions and hallucinations
- fears for their care recipient's safety
- self-isolation through fear of rejection and stigma.

## Restricted opportunities to socialise

Young carers have fewer opportunities to socialise and develop friendships than their peers, resulting in limited social networks (Aldridge & Becker, 1993; Dearden & Becker, 2000; Lackey & Gates, 2001; Thomas et al., 2003). Barry (2011) asserts that young carers "often experience even greater social isolation than other disadvantaged young people because their caring roles leave little time or opportunity for leisure activities or friendship networks" (p. 524).

The New Zealand Youth12 survey found most students (91 percent) had one or more friends who they could talk to about anything (Clark et al., 2013). Having strong friendships could encourage young carers to discuss their caring roles with peers whom they trust. Respite or other services for young carers are important to ensure they have the time to develop and maintain friendships both at school and in their community.

## Low educational qualifications

Young carers' concerns or worries for their care recipient even when they are not physically together (Aldridge & Becker, 2003; Noble-Carr, 2002), combined with low school attendance, can affect both educational experiences and attainment (Banks et al., 2002; Barry, 2011; Moore, 2005).

Across many countries, evidence exists that caring roles can lead to poorer educational outcomes for young carers compared with their non-caring counterparts, especially when teachers are unaware of their caring roles. This may include missing school, early discontinuation of education, or even dropping out of schooling altogether. For instance, in the UK, over one-third of young carers aged 11-15 missed school or experienced problems with education due to their caring role (Dearden & Becker, 1998).

In New Zealand, low educational achievement was reported by over half the social support agency representatives in one young carer study (Ferguson et al., 2001). The New Zealand Department of Labour (2011) found that at younger ages, "carers tended to have lower qualifications than similarly aged people in the general population" (p. 5).

In Australia, only 4 percent of young primary carers aged 15- 25 years were still in education, compared with 23 percent of their peers (Australian Bureau of Statistics, 2009). Bibby and Becker (2000) stress the importance of young carers attending school until the legal school leaving age, unless adequate educational alternatives such as correspondence college or home schooling have been organised.

## Lack of employment

Young carers' lowered educational achievement may limit employment opportunities and lead to increased economic marginalisation because they are negatively placed for participation in the labour market (eg Cass et al. 2011; Dearden & Becker, 2000; Moore, 2005). Higher rates of unemployment for young carers are evident in Australian data (ABS, 2009), which estimates 60 percent of young carers aged 15-25 years are unemployed or not in the labour force, compared to 38 percent for the general population in the same age group.

Although pertaining to all carers rather than young carers specifically, it is interesting to note that in New Zealand, as of 2006, unpaid carers aged 25-54 were less likely to have full-time employment (57 percent) than people of the same age bracket in the general population (66 percent) (Department of Labour, 2011).

For those young carers who find work, a career in caring appears common (eg Levine et al., 2005). One-third of 51 young carers in a US study were nurses or teachers (Lackey & Gates, 2001), and in a UK study, 50 percent of interviewees ascribed their career in a caring occupation to their young carer experiences (Frank, Tatum, & Tucker, 1999).

While being employed in a caring profession is a reputable vocation, Dearden and Becker (2000) emphasise that alternative career options should be accessible for young carers whose caring experiences were negative, or for whom their caring outcomes were unfavourable.

These findings emphasise the importance to support young carers to balance their care roles with their schooling and further education, so that they can attain the required qualifications to be successful in their desired field outside of their care roles.

## Positive outcomes of young caring

Despite negative outcomes of caring being widely cited in the literature, upon a closer examination of the research, positive outcomes for young carers are also evident (Frank et al., 1999; Lackey & Gates, 2001; Levine et al., 2005). Banks et al. (2002) and Noble-Carr (2002) both found young carers may want to carry out their care roles for the time period warranted by their care recipient. This is evident in one male 16-year-old young carer's comment in Barry's (2011) Scottish study; "it doesn't really feel like a chore, because rather than feeling I have to do it, I feel I want to do it" (p. 528).

Young carers enjoyment of their caring role is cited again in Shifren (2001) and Shifren and Kachorek (2003), with more positive than negative mental health reported by their 24 former young carer participants. Aldridge and Becker (1993) found young carers "often value and cherish their family life and their caring experiences" (p. 79). Lifelong memories and gaining a sense of self-respect were positive factors associated with the caring roles of 47 participants aged 18-40 years in Dellmann-Jenkins, Blankemeyer, & Pinkard's (2000) study. Furthermore, Aldridge (2009) realised "child-parent relationships can be strengthened by children taking on caring responsibilities" (p. 38). Similarly, Barry (2011) found "being a young carer was seen as a definite bonding mechanism between the young person and his/her family" (p. 530).

The Caring for New Zealand Carers report found young carers "often gain diverse and rich life experiences for their caring role which can benefit them later in life" (MSD, 2007, p. 15). Other positive aspects of being a young carer include resilience in the face of adversity, and the development of compassion and empathy (Fergusson et al, 2001; McDonald et al., 2009). Positive outcomes of caring are certainly apparent, particularly in terms of the formation of strong relationships among family members.

## What supports work for young carers?

### Information for young carers

Access to age-appropriate information pertaining to the young caring role, and material outlining possible services for the young carer and their care recipient, are key supports identified in the literature (Cass, Smyth, Hill, Blaxland, & Hamilton, 2009; Forrest Keenan, Miedzybrodzka, Van Teijlingen, McKee, & Simpson, 2007). In addition, Australian researchers Moore (2005) and Noble-Carr (2002) found young carers wanted – but had not received – information about their rights as children and as carers.

Frank (1999) states that information resources for young carers should address the following:

- services available for the young carer themselves and their care recipient
- who the various professionals coming into the home are, and why
- financial support available
- who to talk to about specific support needs, for instance a counsellor
- health and safety advice, for instance lifting in the home.

Cooklin (2010) highlights the need for the information to help young carers to understand that:

- the health condition or disability of their care recipient is not their fault
- they cannot 'catch' the health condition or disability
- their situation is not uncommon.

Frank (1999) also highlights that information provided to young carers should be:

- offered in a timely manner
- age-appropriate
- jargon free and without too many acronyms
- accessible in numerous formats and languages
- showing respect for the rights of the care recipient.

A key information document for young carers is the latest *Who Cares? We Do: Info & Advice for Young Carers* booklet (2014) created by Carers Australia. The document offers information in a vibrant and interesting magazine format, and includes information such as:

- looking after myself better
- getting a better sleep
- rewarding myself once in a while
- dealing with stress
- taking time out
- coping with school
- caring safely
- support from my doctor.

## Disseminating information using technology and popular media

The Disabilities and Carers Collective (2006) highlights the importance of information promoted in ways young carers will notice and understand. Utilising technology and popular media is a key means of distributing information to young carers. Traditional centre-based support needs to be supplemented with mobile and social media services – such as smart-phone applications and social networks – if young carers' needs are to be met. Dearden and Becker (1998) assert face to face conversations can be intimidating to some young carers and may actually impede them opening up and asking for support.

Utilising technology and social media may be a key means of accessing hesitant young carers. Facebook, Skype, and interactive Websites present a potentially powerful medium through which young carers can be identified, and non-intrusive and flexible services can be offered. Although it is important to keep in mind the complexity of providing age-appropriate services, there is a need to ascertain the most effective and ethical ways to use web-based, mobile, and social media technologies to engage a widespread group of largely unrecognised young carers.

## Information provided to disability, welfare, health, or education fields

According to the Disabilities and Carers Collective (2006), workers in the disability, welfare, health, or education fields are often unaware of how to identify or support young carers. Frank (1999) highlights key areas to disseminate the information as:

- doctors surgeries
- discharge point in hospitals
- schools and education centres
- community centres and community notice boards
- libraries and leisure centres
- religious and spiritual meeting places – for instance, churches, mosques, and maraes
- youth clubs.

In particular, information needs to be provided to teachers at all levels of education. Carers Australia's (2008) Young Carers Research Project found "only 4 percent of primary young carers between the ages of 15 to 25 years remain in education compared to 23 percent of young people in the same age group" (p. 2).

The Disabilities and Carers Collective (2006) booklet on carers in higher education offers several recognition and awareness strategies for staff and students to assist young carers to remain in education, including:

- facilitation of greater staff and student awareness of young caring
- generating staff understanding of key identifiers of young carers
- resources and information to assist staff in dealing with issues faced by young carers
- equipping staff with knowledge of the key services available to young carers, so they can highlight those services to young carers in need.

In Barry's (2011) UK study, school-aged young carers identified specific teachers who had been aware of their caring situation and who were supportive, understanding, and flexible with schoolwork deadlines where necessary. Carers Australia's *Supporting Young Carers in Secondary School* booklet outlines key benefits of young carers being identified in their care roles, as teachers were able to:

- become considerate of young carers' home situations
- support young carers through education
- give appropriate advice and information.

## Education-related financial assistance

The Young Carer Bursary Programme is a new initiative by Carers Australia, aimed at helping young carers to combine education with their caring responsibilities. Young carers are defined as:

> "children or young people aged from 12 to 25 who help care in families where someone has an illness, a disability, a mental health issue, an alcohol or other drug problem, or who are frail aged. Young carers may help out with cleaning or cooking, getting a relative or friend about the house, helping with medication, keeping them safe, showering or dressing them, or just watching out to make sure they're OK" (Carers Australia, 2015a).

The bursary works much like a grant, offering up to AUD$10,000 to cover a range of educational items including course fees, text books, tutoring, school uniforms, extra-curricular activities, respite support, accommodation or transport, emotional support, or to alleviate the financial pressure on young carers to undertake part-time work. No data is available yet concerning the uptake of the bursary.

To be eligible for the young carer bursary, applicants must be:

- aged 12 to 25 years
- at least at secondary school
- not in receipt of another bursary or scholarship
- not already qualified with a Degree or Advanced Diploma
- an Australian citizen or Australian permanent resident (Carers Australia, 2015a).

Additionally, young carers must be training or studying an approved course (full-time or part-time). Post-graduate university courses and advanced diplomas are not eligible courses for the bursaries.

Approved secondary education courses include:

- an accredited course through a secondary school or TAFE, higher education institution or special school
- an 'English as a second language' course
- preparatory courses for tertiary education
- school-based apprenticeship or traineeship
- some language, literacy and numeracy courses (Carers Australia, 2015a).

Approved tertiary education courses include:

- statement of attainment and other accredited training programmes
- tertiary level Open Learning courses
- certificate and advanced certificate courses
- diploma courses
- undergraduate bachelor degree courses and honours years (Carers Australia, 2015a).

Finally, some vocational and educational training courses, including apprenticeships, are approved for the bursary (Carers Australia, 2015a).

## Peer groups led by former young carers

According to Noble-Carr (2002), young carers in New Zealand need more opportunities to both access and build informal support networks. The development of a support group led by former young carers may be effective in assisting children who care to come forward and identify as young carers, and subsequently seek information about their role.

Noble-Carr (2002) also notes that support groups need to be based on clear protocols and principles that reflect the rights of young carers and their families. Protocols and moderation are particularly important in online forums. Support groups via online forums or drop-in spaces led by former young carers could provide safe, impartial and non-judgmental counsel for young carers from a position of understanding and lived experience.

During 2014, the Ministry of Social Development contributed funding for the development of a Facebook page for young carers. By December 2014, the Facebook page had over 2,000 "likes". Further support for young carers – in particular, support for their information and learning needs – is in development under the Carers' Strategy Action Plan. One of the key purposes of this evidence brief is to inform these developments.

## A voice of young carers

A recommendation from Gaffney's (2007) study was that relevant government agencies and non-government organisations in New Zealand engage with and formally support a special interest young carer group, established to discuss and give feedback on young carer-related issues. Such a group would ensure there is a viable national voice for this invisible community of carers. In response to this recommendation, Young Carers' New Zealand (YCNZ) Convenor Lauren Donnan established the YCNZ Advisory group in November 2014, under the guidance and financial backing of Carers New Zealand CEO Laurie Hilsgen. The Advisory Group comprises six demographically, ethnically, and regionally diverse current and former New Zealand young carer members. Together, the group has experience caring during childhood and adolescence for parents, siblings, and grandparents, whose care needs include mental illness, physical and intellectual disability, autism, substance abuse, frailty of age, and specific illnesses such as Cancer and Angelman Syndrome. The YCNZ Advisory Group is an effective starting point to discuss the information and learning needs of young carers. The group is anticipated to continue to expand in size and influence the coming years.

### Identifying young carers

The Multidimensional Assessment of Caring Activities (MACA-YC18) tool is a simple, child-friendly, and accessible questionnaire with an 18-item self-report measure, for the assessment of caring activities in children and youth (Joseph, Becker, & Becker, 2009). The MACA-YC18 tool, used to identify young carers, is often supplemented with the Positive and Negative Outcomes of Caring (PANOC-YC20) tool (Joseph et al., 2009). The PANOC-YC20 tool, with a 20-item self-report measure, can provide an indication of positive and negative outcomes of caring for identified young carers. Both tools are for use by professionals in the fields of health and social care, in order to assist in identifying young carers, and establishing the outcomes of caring during childhood. More than 6,000 responses to the MACA-YC18 questionnaire were received in the UK, identifying the need for further supports for young carers. In the New Zealand context, the MACA-YC18 tool in particular is useful for teachers, GPs, and social services workers, to identify young carers.

## What doesn't work?

- providing information without widely advertising its existence and availability.
- information in hard copy forms only (eg brochures), disregarding social media forms.
- information created without young carer consultation on what they need and what is appealing.
- information provided that does not reflect the cultural contexts of young carers.

## Research, policy, and legislation

### Lack of research and evaluation

The need for more research is a strong theme across the literature (eg O'Connell et al., 2008). According to Olsen (1996) "in-depth ... research, designed to enhance our knowledge of who young carers are, what they do, and how they do it, is more urgently required" (p. 49). Gaffney's (2007) New Zealand study outlines young caring as an "area of concern" requiring further research (p. 7), and is supported by McDonald et al.'s (2009) New Zealand study, which concludes; "further qualitative research with a broader range of young carers and their families will increase our understanding of their lives and experiences" (p. 126).

Lacking in current New Zealand research are studies with participants of diverse backgrounds that afford agency to young carers by accessing their own conceptions of their roles and support needs, including during and after their transition to adulthood, and which contribute to relevant public policies and practices.

While steps have been taken in the UK and Australia to assist young carers and their families, the UK National Carers Strategy points out that there are no detailed evaluations of the different approaches and their impact on young carers and their families (HM Government, 2008). The following discussion on the policies and services offered in the UK and Australia, therefore, lacks supporting evidence on their effectiveness due to a lack of evaluation.

## Policies in the UK

Since the 1990s, policy and legislative changes have been carried out in the UK to address the invisibility of young carers in service delivery (Aldridge & Becker, 2003). The most notable of the judicial changes are:

- the Carers (Recognition and Services) Act in 1995, in which carers of all ages were given the right to an assessment of their capacity to deliver care now, and into the future
- the 1999 National Carers' Strategy that stipulated development of improved counselling services for young carers, and called for further young carer projects to be carried out
- the 2000 Carers and Disabled Children Act, which gave carers over 16 years of age who were caring for a person over the age of 18 years, the right to a needs assessment for themselves, even in the case where the person in their care did not request an assessment, and greater access to respite services.[4]

## Policies in Australia

The Young Carers Program, run by Carers Australia, specifically addresses young carers' needs, by offering information, advice and support for young carers. The inaugural young carer summit was held in Sydney in 2004 and hosted 60 young carer participants, aged 13 to 24 years (Carers Australia, 2005). The summit presented young carers with the opportunity to have their voices heard by government representatives and key service providers who have the capacity to effect change (Carers Australia, 2005). A key outcome of the summit was a budget increase targeted at respite and information assistances for young carers (Carers Australia, 2005). The implementation of the funding is apparent in the information packs, websites, and services now available. The summit continues to be held at regular intervals.[5]

## Policies in New Zealand

A marked absence of public policies and services addressing young carers' needs is evident in New Zealand. The inaugural Young Carers New Zealand national forum was held in Auckland in 2005, and was anticipated to run every two years thereafter; however, the inaugural forum remains the only one of its kind.[6]

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[4] See also page 39 in addendum.

[5] See also page 40 in addendum.

[6] See also page 40 in addendum.

## Examining the interface between young carers and vulnerable children

In the Children's Action Plan *Vulnerable Children and Families* Green Paper (Statistics New Zealand, 2012), 11 factors considered to adversely affect children's development or well-being are identified; the accumulation of which results in vulnerable children. Four of those factors are key to young carers:

- sole-parent households
- low economic standard of living
- poor mental health
- income from a benefit (for instance Supported Living Payment).

Furthermore, both periods when children are identified as being especially vulnerable can apply to a carer: when they are very young, and when they enter adolescence (Statistics New Zealand, 2012). Examination of the interface between young carers and vulnerable children policies in New Zealand is pertinent, while being mindful of the low profile young carers are likely to have within the larger umbrella of vulnerable children.

## Citations for key documents used in evidence brief

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# Appendices

## Personal Background Relevant to the Evidence Brief

In 2013, the author discovered that she was a young carer. Despite 11 years of caring for her eldest brother, who has autism and an intellectual disability, she had never heard the term young carer, received formal recognition or assistance, nor met another young carer. The author happened upon the international young carer movement when commencing her doctorate in the disability field, and she strongly identified. Her caring experience, and the invisibility of her role, strongly resonated with other young carers' experiences cited in literature (Aldridge, 2008; Barry, 2011; Eley, 2004; Smyth, Blaxland, & Cass, 2011; Thomas et al., 2003). She learnt that she was one of the unknown numbers of young carers in New Zealand, carrying out their care tasks in isolation, without proper supports, and without opportunities to connect with one another. Her strong desire to contribute to redressing the invisibility of young carers has led to her research into the experiences and needs of young carers in New Zealand.

## Search Statement

A sustained and extensive literature search across multiple disciplines and fields was completed. Overall, the corpus of literature mostly spanned 1990 to 2014.

The search used a range of nationally- and internationally-utilised care and disability terms with truncations employed to increase search 'hits' (eg disab* to capture disability, disabilities, disabled) that were constantly updated as supplementary terms surfaced. Literature sources included: (a) databases (eg Google Scholar, ProQuest), (b) journals (for which email alerts were created), (c) books, (d) theses and dissertations, (e) policy documents, and (f) government and organisation reports.

Literature sources were accessed from the University of Auckland libraries, and through external organisation library and learning services nationally (Donald Beasley Institute, IHC, Skylight, CCS Disability Action).

Due to the paucity of research pertaining specifically to young carers, the search was later extended to include popular culture representations (eg blogs, social media sites, YouTube videos, newsletters), and the search parameters expanded to incorporate related bodies of literature (eg palliative care, cancer, HIV/AIDS, multiple sclerosis).

To increase the depth of the search, reference lists in key articles were examined, going beyond the initial search corpus by accessing consequent relevant publications. Unpublished and in-progress material was also accessed where possible. This evidence brief therefore represents a wide breadth and depth of research.

# Addendum

## Policies in the UK

Most recently, the UK is undergoing a significant change in young carer legislation, launching both a new Care Act and a Children and Families Act. The new Acts have come about as a response to:

- complex and piecemeal legislation
- inconsistent and limited assessment of young carers
- lack of prevention and reduction of inappropriate care roles for children
- lack of clarity around whether children's or adult's services are responsible for young carers
- enduring lack of identification of young carers (Frank, 2015).

The new Acts are aimed at ensuring that:

- assessment of the needs of the person with a disability or illness is followed by subsequent assessment of the remaining support needs of the family
- the presence of a young carer will trigger an assessment for the person requiring care
- attention is given to whether or not a young carer is a vulnerable child whose "welfare or development may suffer if support is not provided to them and/or their family" (Frank, 2015, p. 3).

The desired starting point for the new legislation is the implementation of the Whole Family Approach (WFA) when assessment is undertaken and consequent services are provided to a person with support needs. The purpose of the WFA is "for local authorities to take a holistic view of the person's needs, in the context of their wider support network" (Frank, 2015, p. 10). Frank (2015) asserts that, "the adult's assessment and eligibility for support should take into account their parenting responsibilities and functioning of the family" (p. 4). A key focus will be on why the child is caring, and what can be done in order to prevent adverse outcomes for the child's education, welfare, and development.

It is anticipated that the new Care Act and the Children and Families Act will achieve the following outcomes for young carers and their families:

- extension of the right to an assessment for the young carer
- appropriate links between children's and adults' legislation
- a whole family approach to assessing and supporting adults with support needs
- a clear legislative framework (Frank, 2015).

Both the Care Act and the Children and Families Act will come into force in April 2015. It will be compulsory for all UK Local Authorities to implement the Acts after 1st April 2015 (Frank, 2015).

## Policies in Australia

Carers Australia advocates for carers on a wide range of issues, and manages the implementation of national programs, support and services for carers in Australia (Carers Australia, 2015b). Carers Australia has worked with both young and adult carers, carer organisations, the government and key stakeholders to develop and deliver counselling, advice, information and registration services for young carers. Key examples of "informal" carer services offered by Carers Australia that also address young carers' needs are:

- Better Start, which provides information concerning funding and possible support services for carers of children with disabilities
- The National Carer Counselling Program that offers short-term qualified counsellor sessions for carers
- The Mental Health Carer Counselling Program for carers of people with mental illness (Carers Australia, 2015b).

The recent Young Carer Bursary, discussed earlier in this evidence brief (page 21), is another key initiative by Carers Australia, aimed at helping young carers to combine education with their caring responsibilities by offering financial support.

Most recently, Carers Australia has tendered a submission to the Federal Government that recommends several actions for "informal" carers, including young carers, to be incorporated into the 2015-16 Federal Budget (Carers Australia, 2015b). The recommendations address the following broad areas for young and adult carers:

- integrating and aligning support services for carers
- 'Falling between the gaps' of the National Disability Insurance Scheme (NDIS)
- effect of social security reform on "informal" carers
- supporting former carers to enter or re-enter the workforce
- helping employed carers to successfully combine work and care (Carers Australia, 2015b).

## Policies in New Zealand

The recently established group Young Carers New Zealand (YCNZ), and the subsidiary Young Carers Advisory Group (discussed earlier in the brief on page 23), together with Carers New Zealand, are working together with the Ministry of Social Development to address the information needs of young carers.