Final Report

A research study of Young Carers: The development of a recording tool for agencies to identify young carers

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Executive Summary

The Children's Issues Centre, on behalf of Carers New Zealand, undertook this research project. The Ministry of Health funded the project.

The review of literature describes the emerging field of young carers research that is now reasonably well established in the UK, has begun to develop in Australia, but is a new topic of study in NZ.

For the purposes of this project young carers have been defined as:

- Children up to 17 years of age who have the sole or significant joint caring responsibility for another person.
- The person being cared for would usually have a physical, mental or genetic impairment, an illness or be frail of age (we did not include teen parents).
- The level and regularity of care provided is more than might be expected of children of a similar age, gender or cultural affiliation.

As there were no immediate means of identifying young carers, as was available for research in the UK, this project undertook to develop a recording tool for social service agencies so that they could be supported to identify young carers as part of their ongoing work.

The tool that was developed includes most of the factors that overseas research has identified as being important when understanding the role of young carers. It asks agencies to: describe the family, identify the types and amounts of tasks being undertaken by children, describe the impact the caring role has on the child, and indicate what type of supports are currently available.

Four agencies worked with the researchers to find a way of incorporating the tool into their assessment processes. Information relating to 'young carers' from these assessments was then provided back to the researcher to get a better understanding of what was happening for these children in respect of their caring role.

The diversity of interventions used by services explained the variation in approaches to assessment. This meant that on a sensitive topic such as 'how much care children are providing at home' establishing how much they are doing and what kind of roles they are undertaking is very difficult. Over time as agencies get to know families and family members build trust in the agencies then more information is shared. Thus the timing of assessment is critical.

The four agencies involved identified between 1-15% of their client group as involving young carers. Only a small number of the children were taking on a primary caregiving role, the majority were in a secondary role where they supported another adult caregiver. The people providing the information felt that the types of tasks or the amount of care being provided by all children identified was more than would be expected of children of a similar age, gender or cultural affiliation.

The discussion reviews some of the issues agencies face when attempting to identify young carers and recommendations are provided for future work. In particular, the

understanding of the role of young carers requires not only an assessment of the child or young person, but also an understanding of the whole family and the balance of care within before interventions can occur.

The author recommends that:

- a survey is conducted to determine the current range of domestic and caring roles that children in general undertake within NZ families.
- the Ministry of Health and Carers NZ continue to work together to raise the profile of young carers with social service agencies so as to remind them to consider this dimension of children's lives. This would include specific mention of young carers being made in new government strategies, policies and legislation relevant to carers.
- the relevant government agencies and non-government organisations responsible for the well-being of young carers engage with and formally support Young Carers New Zealand, which has been set up as a special interest group under the auspices of Carers New Zealand. This is to ensure a viable national voice for this invisible community of family caregivers.
- an evaluation is conducted to determine the impact of interventions on young carers to indicate what challenges children face even when the family member with impairments or illnesses is supported.
- more conceptual work is done to establish the most useful means of engaging with families whereby everybody's needs are considered during the assessment and intervention processes that follow.
- case study research involving children, parents and whānau and agencies are included to provide a more complete picture of family life involving young carers. This would also include research into the outcomes for young carers as they make the transition to adulthood, including employment and tertiary education.

Introduction

This research project was initiated to explore an area of concern raised anecdotally about children who take on a significant caring role within their family or household. This is often associated with parents who have a significant disability or illness. The purpose of the research was not just to identify these children within the context of a research project but also to raise awareness within social services so that such children do not remain invisible.

> **The first aim is to develop a recording tool for agencies to use to identify young carers.**

As part of developing a recording tool the intention was to achieve information on the numbers of young carers in Dunedin and their characteristics, e.g. age, type of care they are providing, who they are caring for, the impact on their development and so on.

> **The second aim is to broaden society's understanding of young carers.**

The long-term aim is to begin to identify the numbers of young carers in New Zealand that will provide information for policy and service development.

Reviewing 'young carers' literature

Much of the research, of the small amount that has been done, around children in the role of carers has come out of the Young Carers Research Group (YCRG) at Loughborough University established in 1992. Since then they have conducted many studies in the UK to establish Young Carers as a legitimate area of research. As a result of research and advocacy in the 1980s the Carers National Association initiated the Young Carers Project (Project) funded by the UK Department of Health. Young carers were then given more recognition in the UK when the Carers (Recognition and Services) Act 1995 was passed. They were explicitly recognised as being eligible to have an assessment in their own right (Dearden & Becker, 1998). Most Projects are provided by the voluntary sector but do receive statutory funding and local body support (Dearden & Becker, 2000). How Projects run varies across the country as they "have developed independently and are designed to meet local needs" (Dearden & Becker, 1995, p. 31).

> Most projects provide information and avenues for accessing other forms of support, as well as counselling, advocacy and befriending services. Befriending schemes can be informally arranged, providing young carers with a 'listening ear' when the need arises. Or they can be formally organised, one-to-one friendships with volunteer befrienders.
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> Advocacy is a crucial part of the work of many projects as the majority of young carers are unaware of their rights. Project workers either work alongside young carers or advocate for them to try and secure their rights under existing legislation, particularly the Children Act and Carers Act. In this way, project workers can also try to ensure that the needs and rights of other family members are met. (Dearden & Becker, 1995, p. 51)

As projects are also providing services based on children's expressed needs organising leisure activities is another important means of support. Dearden and Becker (1998) noted that the Projects did not have an ongoing source of funding making their future sustainability doubtful and this had not changed according to the most recent report (Dearden & Becker, 2004).

The YCRG have focused their attention on children under the age of 18. The Carers Act 1995 defines carers as those who ‘carry out a significant caring task’. Dearden and Becker originally distinguished between those with primary responsibilities and those with secondary responsibilities (Dearden & Becker, 1995) but now give more attention to the impact of the caring role on the child. Elsewhere in the absence of legislation significant care has been used in an Australian study to define those who have the primary caring role (Carers Australia, 2001a). The difficulty with using Projects to collect information about young carers was that they have developed independently and as a result there is no guarantee that they all use the same definitions in terms of access and assessment.

Dearden and Becker (1995) conducted a national UK survey of Projects to establish the number of young carers using them and the young carers’ characteristics. The 26 responding projects provided information about 641 young carers. Two years later they conducted a similar survey with 86 projects this time providing information about 2303 young carers (Dearden & Becker, 1998). In the most recent survey in 2003 there were 87 responses covering 6178 children, a response rate of 38 percent (Dearden & Becker, 2004). The estimates of the number of young carers in the UK vary from 10,000 to 50,000, but census data from 2001 ‘suggest a figure of 175,000 young carers nationally’ (Dearden & Becker, 2004, p. 4) This is from the pool of 3 million children known to be living in households “where a family member is hampered in daily activities by a chronic physical or mental health problem” (Dearden & Becker, 2001, p. 231). The general profile of the children surveyed across the three years is shown in Table 1 over the page.

One of the challenges in characterising young carers by what they do is finding some agreement across the categories of care. Dearden and Becker (1995, 1998, 2004) use the categories of: (a) domestic care, household tasks that are completed in any family such as washing up and cooking; (b) general care, tasks done specifically to support the person requiring care in the family, which included administering medication or mobility; (c) emotional care, the most difficult to define, but includes monitoring and supporting parental mental health; (d) intimate care, involving toileting and bathing; (e) childcare, which is looking after siblings; and (f) other care, including paying bills and dealing with the mail or phone calls. There are challenges, such as at what point ‘affectionate and caring behaviour’ should be defined as ‘emotional care work’ (Carers Association of Australia, 1997).

Dearden and Becker have noted that over time Projects were receiving more referrals for children caring for siblings. In the eight years between the first and third survey the referrals for this group have nearly doubled. This was also reflected in the increasing number of care recipients with learning difficulties. Percentages of caring tasks in Table 1 add to more than 100 because carers are undertaking more than one type of task. One of the features of the 1997 survey was that where care recipients had physical disabilities then domestic, general and intimate care were the types of tasks most often reported as being provided. Where care was for someone with a mental illness then providing domestic and emotional support was most likely to be reported. Those caring for people with learning or sensory impairments are most likely to report providing domestic and general care (Dearden & Becker, 1998). These patterns were repeated in the 2003 survey, the only major difference not accounted for by the authors was the large increase in children reported as providing emotional support (Dearden & Becker, 2004). It appears to be a result of how this question was asked. In the earlier surveys emotional support was taken as a group from the ‘other’ tasks that respondents reported. In the latest survey it was offered as a distinct task defined for the respondents as "observing care recipients' emotional state, providing supervision or trying to cheer them up when they are depressed etc" (Dearden & Becker, 2004, p. 7). Having provided the definition explicitly the task was reported almost 100 percent more often in the 2003 survey (see Table 1 below).

Table 1: UK young carers survey data – comparison of 1995, 1997 and 2003.

	1995 survey % (n=641)	1997 survey % (n=2303)	2003 survey % (n=6178)
Age	Average age = 12 80% of compulsory school age (5-15 yrs)	Average age = 12 86% of compulsory school age	Average age = 12 86% of compulsory school age
Gender	61% female 39% male	57% female 43% male	56% female 44% male
Ethnicity	90% white, 5% black	87% white, 7% black	84% white, 3% black
Family structure	60% sole parent families (23% of UK children lived in sole parent families in 1995)	54% sole parent families	56% sole parent families
Who are they caring for:	61% mother, 17% father 17% sibling 5% other	58% mother, 13% father 24% sibling 5% other	52% mother, 14% father 31% sibling 4% other
Nature of illness or disability of care recipient	Physical = 60% Mental = 29% Learning = 6% Sensory = 4% Other = 1%	Physical = 57% Mental = 25% Learning = 11% Sensory = 3% Other = 3%	Physical = 50% Mental = 29% Learning = 17% Sensory = 3% Other = 1%
Caring tasks	Domestic = 65% General Care = 61% Emotional Support = 25% Intimate Care = 23% Child Care = 11% Other = 10%	Domestic = 72% General Care = 57% Emotional Support = 43% Intimate Care = 21% Child Care = 7% Other = 29%	Domestic = 68% General Care = 48% Emotional Support = 82% Intimate Care = 18% Child Care = 11% Other = 7%
Types of services received beyond involvement in Young Carers Project	Social work = 51 Respite = 5 Home care = 14 Nursing = 10 Educational = 5 No other = 20	Social work = 47 Respite = 9 Home care = 16 Nursing = 16 Educational = 5 No other = 25	Other data not reported No other = 21
Who made referrals to the Project	Social workers = 37 Family members = 12 Educ/welf officers = 7 Teachers = 6	Social workers = 38 Family members = 16 Educ/wel officers = 7 Teachers = 6	Data not reported

Most of the families with young carers are receiving some kind of support beyond what is provided by the Young Carers Projects. The authors, however, did note that a quarter of the group during 1997 were receiving no other support (Dearden & Becker, 1998). This was important because "The availability of external support and services to young carers and their families play a critical part in influencing what, and how much, young carers must do within the home" (p. 20). In the other two surveys the percentage of those not receiving services was twenty. Project workers aim to develop relationships with families, as well as the young carer, with the result that in order to support the children the workers are also ensuring families gain access to services that they did not know, they had a right to.

The Carers Act allows all carers to have their needs assessed at the same time as a care recipient. (This is not a feature of the current NZ Needs Assessment and Service Co-ordination system [NASC].) The Act says that those providing 'substantial' or 'regular' care have a right to this. It is up to local authorities to define what this might mean (Dearden & Becker, 1998). The authors report that the practice guide to support the Act makes specific reference to assessing children in the role of caring. The Act also acknowledges that outcomes for children who have a caring role should be accounted for when assessing their needs so as not to limit the assessment to just those whom are providing regular and substantial care. When conducting the second survey of Projects which was into the second year after the Act had been enabled (1996) only 11 percent of the 2303 children had been assessed, 43 percent of this group under the Children Act (1989) and 35 percent under the Carers Act (some children were assessed under both) (Dearden & Becker, 1998). In the 2003 survey 18 percent had been assessed. The Children Act (1989) allows young carers to be assessed as 'children in need' (section 17) or 'children at risk of suffering likely or actual significant harm' (section 43). It was not clear which part of the act they were assessed under (Dearden & Becker, 2001) and this is also the case in the third survey, when it is unknown if children are assessed as a child protection concern or as carers.

There were very few differences across the surveys as to which Act young carers were assessed under. In the 1998 survey young carers are more likely to have had an assessment if they are caring for someone with a mental health problem. Those students who are having educational difficulties or are missing school are twice as likely to have been assessed than those who are attending regularly. That said, children who are young carers do not appear to come to the attention of school or education authorities either in terms of the referrals made to Projects (Dearden & Becker, 1995, 1998) or in the numbers of students having achievement problems being identified by schools (GHK Consulting, Holden McAllister Partnership and IPSOS Public Affairs, 2004). The 2003 data indicated that the educational impact of caring was continuing to decrease with 50 percent fewer young carers being reported as missing school or experiencing difficulties compared to the 1995 data (Dearden & Becker, 2004). Dearden and Becker (1998) reported that the children, in the main, found the assessment process, conducted by social workers, useful and resulted in the appropriate improvement of services. The 2003 survey shows that young carers were more likely to be assessed if they were in a lone parent family, especially a black or minority ethnic family or in a family where a relative has problems with drugs or alcohol.

Dearden and Becker (1998) highlight one caring task and one outcome as indicators that young carers are not receiving enough support:

> However, one in five young carers still has to perform intimate caring tasks for a parent or other family member – tasks which are often

> profoundly embarrassing to both parties – a third of young carers of secondary school age are missing school or have educational difficulties…. (there) is still a very large number of individual children whose lives are being affected, often negatively, by their caring experiences, roles and responsibilities. (p. 82)

Although earlier in the same report they acknowledge that children generally note intimate care is embarrassing when it is cross gender. In the third survey Dearden and Becker (2004) point out that both these indicators are improving for young carers in comparison to the first two surveys.

As mentioned earlier Dearden and Becker (1998) noted that levels of assessment under the Carers Act two years after its implementation for young carers was low and that this was also the case for adults, and therefore not necessarily a failure of policy in relation to young carers but carers in general. Government support for the Children Act continued with the release in 2002 of *Framework for the assessment of children in need and their families* (Department of Heath, 2000). This document advocates assessment that looks at children's developmental needs, the parenting capacity within families, and family and environmental factors. This model is placed in a child centred and ecological approach to assessment. In the same way Dearden and Becker promote a holistic approach to assessment as it reduces the "more negative consequences of young caring" (Dearden & Becker, 2001, p. 226). However, they report that having a number of Acts within which to operate as well as local authority variability in understanding of how the Acts might apply to young carers has led to difficulties in raising professional awareness and establishing professional responsibility for conducting assessments (Dearden & Becker, 2001).

> Thus assessment must balance children's protection against their needs to remain within the family unit and their needs for support and information. Assessment processes will need to be viewed as a positive way of supporting families and recognising their strengths as well as their weaknesses. Disabled parents must feel that their needs and rights will be taken into account and promoted, and that their parenting abilities will not be questioned inappropriately. Equally, young carers must feel that their abilities as carers are acknowledged and valued and that they are not patronised or ignored in the decision-making process. (Dearden & Becker, 2001, p. 230)

The framework for assessment would seem well placed to acknowledge the complexity of family life, the real challenge seems to be working within the current infrastructure, both legislative and service provision, to get consistency of implementation.

The YCRG has also implemented and evaluated interventions to support young carers. They set up a 'Befriending Programme' that drew on the experiences and resources of a family centre to recruit volunteers to work with a Young Carers Project who identified young carers who wanted to participate. Befrienders were allocated to support workers for supervision. The success of the programme was dependent on the quality of the relationships developed by the befrienders with both family and the young carer as well as with the support worker. It was felt that the arrangement offered respite from caring relationships and an opportunity for friendship. The young carers in the study were under 13 years of age (Aldridge & Becker, 1996a).

The YCRG acknowledge that preventative strategies for young carers are difficult.

> The causes of child 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 service policy, organization and practice. Many welfare professionals continue to ignore the needs and rights of children and parents in families where parental illness or disability is present. (Aldridge & Becker, 1997, p. 4)

They advocate three phases of intervention

> As a primary offensive, strategies that prevent children being drawn into caring roles in the first instance; a secondary intervention would mean addressing the family's circumstances and needs when children have already adopted caring duties in the home, but would perhaps be able, with the input of appropriate services and support, to return to non-carer status; and tertiary intervention would involve supporting those children who are already caring, and who may be in crisis, from being separated from their families. (Aldridge & Becker, 1997, p. 5)

They report that there are difficulties in establishing interventions because professionals have developed a reputation for removing children from families as a response so that both children and families 'are reluctant to reveal home circumstances'. They support a holistic family approach to intervention that accepts children taking on caring roles as a social reality.

The question of family 'autonomy' and 'rights' is clouded by whether families felt they had alternatives to children taking on these roles. Alongside this is the acknowledgement that children also have rights especially to have their needs considered, have appropriate information made available and be included in decision-making (Aldridge & Becker, 1993). Family support in practice, in a fiscally driven society, has become one of responding to crisis. Crisis has come to mean intervention in a form where state representatives make judgements about whether particular families can no longer function without support. This is an all or nothing approach that suggests the state is unable to find ways to provide family support that families find supportive. Especially for those families who are approaching crisis, but are not in crisis, and cannot access other means of support to avoid moving into crisis (Hardiker, Exton and Barker, 1991).

Dearden and Becker (1997) review situations when young carers have been 'looked after' as a professional intervention, either on a voluntary basis or through court orders. Children being looked after because of their parents' health was the third most common reason given for children entering the child care system, after 'parents need relief' and 'abuse or neglect', accounting for 15% of those who 'started to be looked after' in 1995. They also report examples of where children are looked after as a result of parental illness, often mental, but that is not the recorded reason for going into care. Furthermore, even when care was requested, there was a lot of parental dissatisfaction with the final outcome.

Aldridge and Becker (1997) do not see immediate opportunities to develop primary intervention strategies, not because they do not think they are of value, but as an immediate intervention they think that more success is likely to be found in secondary and tertiary strategies. Other authors would rather focus on the primary strategies (Olsen & Parker, 1997). Dearden & Becker (1997) suggest that all children with parents with ill health or disabilities should be identified as potential children in need under the Children Act 1989. The aim would be to avert them becoming young carers, with the provision of appropriate support, and to reduce the need for those children later having to be 'looked after'. A central question here is to ask to what extent such an approach would undermine or support the parenting role of adult care recipients?

The discussion to this point profiles children caring as the issue with little acknowledgement of what else is happening in these children's lives. Dearden and Becker (1997) acknowledge that poor parental health is associated with a "complex web of social disadvantage because of poverty and deprivation" (p. 17). But the intervention strategies recommended still appear to be responding to the role of young carer ahead of other issues that could well be present in the family. For this reason there has been some debate about the most appropriate way to develop the research of young carers and whether the current conceptualisations adopted are the most appropriate (Morris & Keith, 1995; Olsen, 1996; Aldridge & Becker, 1996b; Olsen & Parker, 1997). In part the debate seems to centre around whether children taking on a caring role is a disability issue or a children's issue. This debate appears to dissolve when such issues are discussed with the family as the unit of analysis.

The YCRG have included research where they have talked with young carers to 'hear' their stories. The team acknowledges the tension between providing protection and supporting young carers' independence. "Only through listening to young carers and observing their experiences and expressed needs do we go some way to resolving this dilemma" (Aldridge & Becker, 1993, p. vii). Good practice guidelines have been developed to help professionals 'listen' to children when providing support. The aim is to ensure that the young carers are acknowledged within the National Service Framework for Children (Underdown, 2002).

The research has also identified how the children appear to be defined in relation to the 'real' client or service user, usually an adult. History records examples of young carers through literature and biography. They have always been there (Olsen, 2000; Aldridge & Becker, 1993). But how to study young carers has been restricted by notions of what it means to care in relation to our current expectations of childhood in comparison to the past? Carers Australia (2001a) report that more recently there are more people with disabilities and that the process of de-institutionalisation and reduced acute care availability has placed more people with disabilities into the community.

The YCRG have wanted to identify children as a unique group within the informal arrangements usually adopted by adults. Aldridge and Becker (1993) criticize the medical literature in relation to young carers because it has very rarely tended to build on evidence available, especially that which involves talking with young children. They feel that a lack of research to give voice to the role of young carers amounts to a 'literature of omission'.[1] In this qualitative study, one of their first research projects, they found that the significant issues for young carers revolved around the lack of choice they had in taking on the role, creating what they call 'a socialization into care'.

For the YCRG the critical feature of children taking on the caring role centres around when intimate care is provided or when the quantity of care given is such that school is missed or children do not get opportunities to develop through play, education and

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[1] In a report on children of parents with a mental illness no reference was made to the role of children taking on a caring role or providing support for the parent, instead the focus was on improving the metal health of the children (Garvin, McAllister & Robinson, 2002). This absence has been noted by others (Carers Australia, 2001a).

health care, because of the competing demands with caring. They identify that while family networks are in place other adults and siblings have abdicated responsibility to young carer and that both family and professionals tend to provide support at times of crisis rather than addressing ongoing and regular demands of care (Aldridge & Becker, 1993). That said, young carers demonstrate a high level of loyalty to those they care for, not just in the tasks they do, but in how they talk about the person they care for. Some of the gaps in providing support for young carers revolve around the lack of information from professionals about the disabilities or illnesses their parents or siblings have, and what services or supports are available. Isolation due to caring and a reluctance to indicate they might not be coping means that the children do not have people to talk with about what is happening. Aldridge and Becker (1993) do not recommend a particular strategy for resolving support for young carers other than responding on a case-by-case basis and acknowledging young carers rights as children based on United Nations Convention on the Rights of the Child (UNCROC). Services for families where a child has taken on or been given the role of carer will not focus solely on the person who is being cared for.

Other research on young carers has started to emerge. In Scotland a group of researchers have conducted a number of studies within specific urban areas in Scottish cities (Banks, Cogan, Riddell, Deeley, Hill & Tisdall, 2002; Banks, Cogan, Deeley, Hill, Riddell & Tisdall, 2001). They have used differing means of identifying young carers including using service agencies, conducting a survey, focus groups and interviews. They have suggested prevalence rates of 3-6 percent of young people (based on a student survey of 11-17-year-olds) may be involved in providing care and “2 percent of pupils were providing a level of care for another family member that would not normally be expected of someone of their age” (Banks et al., 2001, p. 807). However, the lack of details such as response rates to the survey make it difficult to verify how these rates were calculated.

What they did establish is the while many children may be affected by the disability of a family member only a small number of these will be fulfilling the ‘primary caring role’. A useful feature of their work was attempting to understand the quantitative features of caring, such as ‘hours spent’ and ‘tasks undertaken’, and their relationship with the qualitative aspects, such as the subjective impact on the children. In developing their assessment concepts for young carers the group used the amount, the significance for the young person and family and the impact of the caring (Banks, Gallagher, Hill & Riddell, 2002). Their own interviews with ‘young carers’ establish, like the YCRG studies, that the children want to care and that “it would be incorrect to assume that young caring is wrong *per se*” (Banks et al., 2002, p. 243). They also note that services need to work within the ‘hidden nature’ of caring and that the overall aim is to support those who wish to care but this is done by ensuring families are given adequate support to prevent young caring from becoming established. The challenge here would seem to be how to provide appropriate levels and types of support over time that balance children being able to ‘care’ within the family without the children having to adopt a primary caring role. This suggests the notion that secondary caring is appropriate, whereas primary caring is not.

In Australia the Carers Association of Australia (CAA) conducted a series of work to identify young carers. Not all were successful (Carers Association of Australia, 1997). A nationally advertised phone-in drew 60 calls. A school survey of children in the Australian Capital Territory (ACT) was conducted to see what level of care children provided. The open-ended questionnaire format made it difficult to compare responses from children. The aim had been to let children self define what activities they do at home and what it meant for them. The advantage of this approach was that it did not require identifying children as young carers before hand. The result was that half of the children reported caring and one eighth of the total "reported having significant care responsibilities either now or in the past" (p. 8). Like the YCRG the CAA identified the intimate caring tasks as 'quite inappropriate'.

A literature review in an Australian study (Carers Australia, 2001a) acknowledged the differences in family contexts between Australia and the UK. It noted that in Australia three groups exist for which there are no corresponding groups in the UK. The groups included: indigenous Australians, those in rural and remote Australia, and the nominal group of 'culturally and linguistically diverse backgrounds'. In the same way NZ family contexts will be different again and the experiences of those here cannot be assumed to be the same as in the UK or Australia. The Australian study included those aged 18-25 caring for others. In which case talking about young carers can include children and young people. The authors of this work also recognize that young carers have not included another well identified group young parents or young/teen mothers. In one study where these two groups were combined into one category, survey participants in the main focused on the young parents in the group (GHK Consulting, Holden McAllister Partnership and IPSOS Public Affairs, 2004).

Identification of young carers is problematic because it is suggested that social service systems are not set up to recognise them and children and adults do not acknowledge the situation. As one Australian writer commented "We don't know how to treat them so we largely ignore them" (Gay, 2001, as cited in Carers Australia, 2001a, p. 28). That parents are not willing to acknowledge the situation is thought to be the result of parents not wanting to undermine their role and being defined as inadequate (Aldridge & Becker, 1994; Morris & Keith, 1995), and can include an underlying fear of children being removed from families. Those writing from a disability perspective say the problem of young carers only exists because of the inadequate resourcing for parents with disabilities (Olsen, 1996; Olsen & Parker, 1997). Alongside this are others who comment that getting access to resources requires placing the family further into the public domain, which for some is associated with embarrassment and shame.

In 1998 the Australian Bureau of Statistics (ABS) conducted a survey on Disability, Ageing and Carers. Carers Australia accessed the unpublished data to conduct their own analysis. They wanted to get information about 'young primary carers' who they defined as:

> someone up to 25 years of age who is the main provider of care and support for a parent, partner, child, relative or friend who has a disability, is frail aged, or who has a chronic mental or physical illness. (Carers Australia, 2001a, p. 6)

The survey identified 18,800 primary young carers across Australia and another 370,000 people in a shared caring role, but they were not in the primary role. Thus five percent of the young carers were primary carers. Six percent of the Australian population under 26 years of age were in a caring role and 0.3 percent of young Australians were in a primary caring role. It is unfortunate that the survey restricted data collection on many questions to those in the survey aged 15 to 25. Of the 0-25 age group of primary carers two thirds were aged18-25 with the remaining third equally split between 15-17 year olds and under 15 years of age. Using the above figures this would suggest that only 0.1 percent of the under 18 years of age population were young carers in a primary caring role. In a NSW study of 521 young carers (self selected) the largest numbers were found in the 11-15-year-old age group (Carers Australia, 2001a), which is similar to that reported by Dearden & Becker (1998).

Of interest to the current study is how the ABS survey categorized both the type of care and the impact of taking on the caring role. The categories used for tasks performed were: self care, mobility, communication, health care, paperwork, transport, housework, property maintenance and meal preparation. The impact of caring categories include: physical health, emotional and mental well-being, social participation, relationships with peers, relationships with family, finances, education, employment, and transition to adulthood. Carers Australia (2000b) decided to use: health and well-being; social participation; family relationships; financial security; education, training and employment; and transition to adulthood as categories of outcomes. For Carers Australia (2000b) they have recommended future work to focus on the provision of programmes and services, family support and a more co-ordinated government approach to address issues. They also see a need to continue research to improve the understanding of the needs of young carers and increase community awareness.

During the writing of this report a new publication from Australia became available that had many of the same aims as the current study. In particular one aim was to “develop a checklist that can be used by medical, educational and other health care professionals as well as case managers within community organisations” (Murrow, 2005, p. 3). This checklist was developed after a mail survey of a small group of families known to have a child in a caring role. A checklist for young carers to complete was also developed. It is interesting to note that Murrow’s study has identified similar issues as in the current study when trying to identify this hidden group. There are no new answers to these issues in this study, but a broader approach to identification was embarked upon to identify young carers and avoid the difficulties faced by the Carers Association of Australia (1997) research. Of immediate interest to this study was the identification of 311 young carers by social agencies. Two thirds were under the age of 16 which is in contrast with the proportion of young carers across age groups identified by survey methods.

In New Zealand we have not identified any previous research prior to this research being undertaken, other than a small study by medical students conducting an evaluation project (Ferguson, Griessel, Lao, Singh & Ure, 2001). The students conducted a survey of 20 social services of which 14 said they had had contact with young carers in the previous year. They used the categories of domestic, physical, communication, personal, companionship, supervision and medication to describe the types of caring involved. Nearly 90 percent of children were reported to be undertaking domestic work. Just over 30 percent were reported to provide personal care and medication. They used the categories of education, friendship, emotional, health, poverty, family change, responsibility and placement to classify the impact that caring was having on the children. The numbers of children involved were difficult to ascertain as survey participants gave anecdotal estimates of the numbers of young carers that their service had contact with.

During the period that this research was being conducted a post graduate student in anthropology began an M.A. (Loose, 2004) that initially began by focusing on young carers that came to the attention of Department of Child, Youth and Family, but this avenue of finding participants did not work and instead data for the thesis was gathered by interviewing adults who were happy to talk about their experiences retrospectively. What was interesting about the group of adults was that despite the level of care they were providing they never came to the attention of social welfare agencies and had limited external support. As such they constitute a different population from the group that would have had contact with social workers through the Department of Social Welfare.

In a review of 2001 New Zealand Census data by Carers New Zealand and the New Zealand Carers Alliance (2005) it was established that 5 percent of the 15-24 year olds were looking after a member of their own household who was ill or had a disability. Slightly less reported looking after someone with similar concerns who did not live in their own household (4.5 %). This compares with 10 percent of 35-44 year olds which was the age group with the highest proportion reporting they care for someone in their household or 11 percent of the 45-59 year olds who care for someone outside of their household. Another feature of the data was that the proportion of male carers was highest in the 15-24 year old age group (with the exception of the over 80 year olds). For every 10 female carers in this age group there were 8-9 males suggesting that this ratio may also apply in the younger age groups as well. The figures are similar to the data from the Australian Bureau of Statistics data cited where six percent of children under the age of 26 were in a caring role.[2]

Some media attention was also given to the 'plight' of young carers when a young boy was found to be the sole support for his quadriplegic grandfather. The ongoing media attention revealed that there was a lot more to the case than originally presented on TV or in the newspapers, highlighting the complexity of family life of which caring is only a part (White, 2003).

Adding a new term

At this point I would like to acknowledge another field of research that includes young carers. This field is located in the medical and therapeutic sciences and uses the term parentification to talk about children taking on the role of parent.

> Parentification has been described as the expectation that one or more children will fulfil the parent role in the family system (Boszormenyi-Nagy & Spark, 1973). The child may act as parent to other children in the family or may be expected to care for the parent (i.e. role reversal), or both.… not surprisingly, the professional literature tends to emphasise the pathological aspects of parentification, whereas the wider literary scene might indicate that adaptive compensation is possible and even advantageous (Barnett & Parker, 1998, p. 146).

A central focus of parentification is the disruption of the development of secure attachments, a feature of destructive parentification as opposed to adaptive parentification (Byng-Hall, 2002). As a lot of the research is retrospective the work has looked at the outcomes for the children when they are adults. "The focus on the long-term effects represents an 'adulto-centric' bias" (Earley & Cushway, 2002, p. 174). There is minimal cross referencing between young carers research and those

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[2] That similarity must be viewed with caution as the Australian data does not distinguish between carers looking after someone in the same household or in another household. It might be assumed that the Australian data covers both categories. However, the New Zealand data did not indicate how many of the 5 percent of young people who looked after someone in their own household were also looking after someone in another household. This could mean that up to 8-10 percent of the 15-24 age group are involved in either care in their own household or in another.

studying parentification. See Banks et al., (2002) and Banks et al., (2001) who acknowledge the term but do not elaborate on the similarities and differences with the field of young carers research which they work within. Earley and Cushway (2002) were more explicit in acknowledging the two areas, but reviewed the parentification literature to show that it has conceptual and research limitations. They conclude by acknowledging that not all children who take on a significant caring role in the family become parentified and that for certain families the caring role taken on by children could be considered adaptive and contribute to family resiliency. At this time the parentification literature would not seem well developed enough to contribute to the young carers literature, except to say that in some circumstances the role of caring by children for a parent may contribute to unhealthy psychological development based on 'role reversal' in parent child relationships rather than taking on caring tasks per se. The parentification literature, as a result has tended to focus on researching adults where mental illness, including addiction and sexual abuse is evident. This report will not attempt to compare the two fields and will build on the developments in the young carers research.

Conclusion

There is no easy means of identifying young carers in New Zealand as has been available in the UK, and even there the use of Young Carers Projects is not the same as conducting national surveys of households, which would be more ideal. No surveys have been conducted in New Zealand and so for this reason a different approach was considered necessary in conducting research in this area.

There are still issues to be resolved in respect of research conducted to date. Identifying young carers in order to encourage research participation would seem to the first problem. Establishing and defining what makes a child a young carer is difficult giving that all children have a propensity to care in some form. Creating thresholds based on the quantity or type of tasks is problematic as the YCRG recognized. Focusing on choice and the option 'not to care' oversimplifies the process of being socialized into care.

At the same time it is not known what the general population of children are doing in respect of caring and domestic routines. Much of what we are doing is driven by some notion that some children should not be providing the level or type of caring that they are, based on some ideal concept about what childhood and family life should be like. On this basis we can also look to the outcomes of caring to provide a cue that a child's caring role is inappropriate or placing them at 'risk'. Such identification is difficult when there is a continuum of care possibilities and some threshold has to be established to decide when care and protection issues arise. But should support for the family only be provided to prevent this from happening and what of those families who prefer to have a child take on the role?

Method

Preparation

Ethical Consent
Consent from the University of Otago, Human Ethics Committee was applied for in February 2003 and given in March. Part of gaining consent included informing the education co-ordinator of the Te Runanga o Ngāi Tahu about the nature of the project. The runanga requested no further consultation over the project.

Advisory Committee
A working party met every 2 months for the purposes of supporting the research and providing guidance. It was made up of Beatrice Hale (Carers NZ), who took the role of Chair, Pania Tulia (social work student and also with Family Start), Nicola Atwool (Community & Family Studies Dept, Otago University), Vaughan Milner (Presbyterian Support, Otago), Mike Noonan (Relationship Services, previously Catholic Social Services), Anne Bray (Donald Beasley Institute), Ali Holmes (CCS), David Horne (Minutes Secretary from Carers Society Otago). Others have attended meetings from time to time. There have been representatives from groups such as ACC and Child, Youth and Family, which allowed for networking.

Beginning of the research

Michael Gaffney has undertaken the research with the support of Pania Tulia. In the absence of any formal structures already in place to identify young carers, as was available for the UK research, the advisory group formulated a research plan based on asking social services to identify young carers. This approach also meant that the agencies could respond to any needs identified rather than placing this responsibility on the researchers. It also meant that the agencies that participated were having the profile of young carers raised across their staff.

Development of Tool
A tool based on the types of information collected from an Australian survey (Carers Australia, 2001a) and some English work (Dearden & Becker, 1995, 1998) on young carers was put together. The tool aims to be very inclusive in the types of information collected so as to get as much information as possible, but still be relevant to the many possible scenarios that young carers find themselves in. This would include caring for a parent, caring for themselves, caring for someone who does not live with the child or caring for siblings because a parent cannot. The only identifiable group not to be included are teenage parents, usually mothers. This is a recognized group that has been well researched elsewhere (e.g., Yoshikawa, Rosman & Hsueh, 2001).

For the purposes of this project young carers have been defined as:

- Children up to 17 years of age who have the sole or significant joint caring responsibility for another person. This is the age range used by the United Nations Convention of the Rights of Child. (Some studies have used up to the age of 25, Carers Australia, 2001a).
- The person cared for is usually a family or household member or friend.

- The person being cared for would usually have a physical, mental or genetic impairment, an illness or be frail aged (at this point we are not including teen parents).
- The level and regularity of care provided is more than might be expected of a child of a similar age, gender or cultural affiliation.

In the end the final identification is reliant on the professional judgement of the people working in the various services as to when a child has a significant caring role for another. Part of the research will look at some of the issues raised when making such decisions. Defining caring is not as straightforward as it might first appear. The research has used a very instrumental approach in trying to identify caring tasks as part of the assessment. This is based on the approaches adopted in the research about young carers reviewed above, but the broader caring literature acknowledges other possibilities that are not so easily identified. For example, the meaning of a task in one household can be quite different from another, especially where the illness or disability places the 'care recipient' in danger if the task is not completed successfully. The purpose of the task then becomes more important than the task itself (Nolan, Grant & Keady, 1996) and we can see how this would increase the responsibility and potential anxiety for children even though the same tasks were being completed.

The information we chose to collect included: family structure and background; the types of care being provided for others, themselves or family in general; the level of responsibility and regularity of caring; the impact of caring on the child; and what supports are currently in place for the family or child. A copy of the tool is in Appendix One. The assessment tool focuses on the young carer rather than being a full family assessment, which the literature advocates. But we have tried to acknowledge this by allowing for the collection of information about the family that contextualises the role of young carer. Changes were made to the tool over time and the appendix copy reflects those. The tool does not include 'needs assessment' but stops at asking whether support is in place and who is providing it in relation to the child's caring role. There is also an implicit needs assessment component when people are asked to make judgements about the impact that the caring role has on the child. The types of needs that have been identified for young carers relate to information, personal support, practical assistance and social contact (Banks et al., 2002). The reason for not including a needs assessment component is that the research is about identification of young carers and the agencies are already making needs assessments in relation to the type of services they are offering. The challenge for the services is that they may find themselves identifying needs they are not in a position to respond to and so they may have to make referral elsewhere. Likewise, the tool presented here is not an evaluation of the services currently being offered by the agencies involved or the other agencies that may have contact with the children.

As a research exercise the aim was to be as inclusive as possible so that later on if the threshold needed to change as to the criteria being used for the identification of young carers then this could happen, whereas if the threshold for identification is too restrictive early on then children may be missed. The same approach has meant that some children in the UK using Young Carers Projects for support are not there because they are carers but because they are thought by some professionals to be affected by living in a household where there is a member of the family with an impairment or illness.

There is not much information about the assessment of young carers. In the UK the Department of health have released 'Framework for the assessment of children in need and their families' (Department of Health, 2000) which makes reference to young carers as being an identifiable group of children in need. The framework suggested for assessment is based on taking into account children's developmental needs, parenting capacity and family and environmental factors, but how this framework applies to young carers is not elaborated. The principles underlying the framework include being child centred, using an ecological approach, involving both families and children, building on strengths and identifying difficulties, using an interagency approach to assessment and service provision, and being grounded in evidence based knowledge. More recently in Scotland Banks et al. (2002) have been developing work around assessment by evaluating the way services conduct assessments. We have used their approach of trying to identify which children have a primary care role as opposed to a secondary care role where children assist another adult to care for another family member. They also note that even when services have identified children in a caring role the children do not always want to access the services on offer, even if it is just because they do not want to identify as a 'young carer' because of the label.

Principles for conducting the research with social agencies

A number of principles were identified as being important to the way this project was to proceed.

Principle 1: Priority is given to acknowledging a caring relationship between a child and the person they care for rather than on establishing the nature of any impairment or illness etc.

Our concern is identifying a child who is caring for another. Establishing that the person they care for has a disability or illness is not so important. There are suggestions that many people do not recognise or acknowledge that they or someone else has a disability and so a professional diagnosis should not be required of the adult before identifying the children as suitable for this study.

Principle 2: Caring is a normal part of being human. It is expected that all children participate in caring.

Therefore, people are asked to make a judgement on when the caring becomes 'inappropriate' or 'excessive'. Two ways to conceptualise caring is in terms of the relationship – who is the child caring for – or in terms of the tasks undertaken – is it expected that a child would do those tasks. Some tasks and types of caring in and of themselves may not seem inappropriate, but it is only when they are added together that there is a significant impact on the child.

This does suggest that if a child is coping well or the impact is relatively insignificant then they might not be included in this study. As a family may be dealing with multiple issues there is also the difficulty in determining how many of the family processes and outcomes are a result of and contribute to the caring relationship. In the face of uncertainty about assessing a child it is preferable that more children are included even if the impact does not appear great. It will be important for the research to know if there are children who can take on significant caring responsibilities and it not have the same impact as it does for others.

Principle 3: Collecting the data for this project should not interfere with the way agencies continue to go about their work with their clients.

In order to improve the likely participation of agencies in the collection of data the research process should not directly change the way an agency works in terms of its own agreed protocols, philosophy or ethical procedures. An outcome of participating in this research might be that practitioners agree to make some changes to take account of young carers they identify. Another outcome is that in developing client relationships agencies are now more aware of the position some children find themselves in and are then better able to ask questions to ascertain and respond to this.

Finding agencies to participate

The advisory committee discussed which agencies might be appropriate to approach to participate in the research. The aim was to have a range of different type of services who operated in different ways. Based on their recommendation an approach would be made to the service to outline the research and discuss whether participation was a possibility. The initial discussion would be with a team leader and would then involve presenting the research idea to the teams. Four agencies completed participation in the research. Four services decided not to participate, did not reply to initial approaches or did not complete their participation. Table 2 lists the services that took part.

Table 2: The types of services that participated and the number of staff who took part.

Type of service	Number of staff participating
Working with families where children are 0-12	5
Taking referrals for children 5-12	2
Voluntary support group for those with a specific physical impairment.	1
Working with young people primarily but by extension with families	7

Ethical concerns and research issues

All services have indicated that families find the issue of children taking on a significant caring role as sensitive on the basis that it might raise care and protection concerns. For this reason raising the possibility with families about participation in the research is delicate. Agencies do not want to compromise the relationship they are developing with their families. In response to this agencies are told they must decide if and when participation is sought. Some have asked if they might refer families on to the researcher but this then places them in an awkward position should care and protection issues be raised. The original ethical approval from the University of Otago Ethics Committee was given on the basis that the researcher would not collect data directly so that if issues arose, such as care and protection concerns, then agencies could use their own protocols for responding. This would include considering what forms of support could be provided or when other referrals might be appropriate.

Assessment

A major part of the liaison with agencies is establishing and responding to the concerns they have and then identifying within their service the systems already in place that create openings for participating in the research. This usually meant gaining an understanding of the assessment processes that were being used. All of the services said that this group of children is important and so they saw the value of participating in the research. The challenges arose from finding a suitable way of collecting information from services that vary widely in the way they operate. The tool would be adapted slightly as a result of discussions. For example, if the agency only worked with young children and their families than the ‘transition to adulthood’ item on Table 5 would not be included.

As part of the research process each agency was asked to describe how they conducted assessment, how the tool for identifying young carers might fit within their assessment protocols and their experience of using the tool. A summary of each agency covering these elements can be found in Appendix Two.

Results

Below in Table 3 are the types of agencies that participated in the research. Alongside the type of agency is the number of young carers identified as a proportion of the number of clients they worked with over the period. There is also presented the proportion of young carers as a percentage of their total client group and the last column indicates the period over which data was collected.

Table 3: Results of data collection around young carers

Type of agency	Numbers identified	Percentage	Period data collected
Working with families where children are usually pre adolescent	2/130 families	1.5	Full year
Taking referrals for children 5-12	5/35 children	14	Full year
Voluntary support group for those with disability	2/250 families	1	Not applicable
Working with young people primarily but by extension with families	9/80 young people	11	4 months

A total of 21 children were identified as possible young carers. The responses from agencies indicate that the percent of the young carers across their client group varied between 1-15. The lowest percentage of 1 is likely to reflect under-reporting as people in this group were asked to self identify rather than the agency worker making the judgement or asking the questions.

Information about the children.

The information provided above was not always followed up by more detailed information from the assessment tool. This was because while the agencies may identify someone as a young carer they did not always feel they were in a position to talk with the child, young person or their family about this role.

Information was received for 12 children in seven families. Not all children had a caring role that met the criteria. Data was reviewed to ascertain which children in the family were doing the caring tasks. The result was that 9 children from 6 families were identified as taking on a significant caring role in the family or higher than might be expected of children of a similar age, gender or ethnicity. The data for this group of children identified by agencies as young carers is summarized below in Table 4. The median age is 11 with the youngest child being 7 and the oldest was 14. Six of the children were girls and three were boys and just over half of the groups were from European/ Pakeha families.

Table 4: Data summarizing young carers identified by agencies.

Factor	Number
Age (years)	14 =1, 13 = 2, 12=1, 11= 2, 10=1, 9 = 1, 7 = 1 median age is 11
Gender	6 females 3 males
Ethnicity	5 European, 4 Māori
Family structure	2 sole parent families (2 fathers) 4 two parent families (1 family was grandparents)
Who are they caring for:	1 mother, 6 fathers 1 sibling 1 other (grandparents)
Nature of illness or disability of care recipient	Physical = 3 Mental = 2 Learning = 2 Sensory = 1 Other = 1
Caring tasks	Domestic = 9 Emotional Support = 6 Medical Care = 0 Intimate Care = 4 Social support = 4 Child Care = 4 Care for themselves = 8 Other = 0
Level of care	Primary = 3 Secondary = 6
Types of services received by family	Social work = 2 Respite = 2 (for children) Home care = 2 Nursing = 0 parenting = 0 No other = 2 (1 family identified as rejecting support offered)
Impact	Physical = 5 Emotional = 9 Educational = 5 Social participation = 7 Peer relationships = 5 Home relationships = 6

Two families were sole parent arrangements with half of the two parent families involving grandparents. Most of the people being cared for were fathers and the most common form of impairment was physical. Only 3 of the children were in the role of primary carer and two of these children had a sibling providing care in a secondary role. All children were providing domestic care with emotional support also being common. All children, but one, were also caring for themselves. Primary care was established on the basis that children were assessed as taking the main role in the family for the tasks listed in Table 2 of the assessment tool (see Appendix One): personal/intimate care, emotional support, medical care and social support. In families where there was more than one child the care responsibilities were usually not shared equally. Most of the families were receiving some kind of service in support of care. The most commonly reported impact on the children was emotional with restricted social participation and home relationships being common as well. Over half were reported as having schooling and physical concerns as well.

Working with the agencies

In Appendix Two there is a profile for each of the agencies that we worked with. Each one matches one of the agencies listed in Table 3. These profiles were developed over a period of consultation and then someone in the agency checked it accuracy and comments on the process of using the tool. The headings used are *Background*, *Assessment*, *How the service might use the tool* and *Their experiences with the tool.*

Each agency worked differently so that in terms of assessment processes no service worked in the same way. A lot of attention had to be given to establishing how the assessment tool that the research was offering could fit within the agency protocols already in place. A critical question for agencies was ‘when would we have developed a secure enough relationship with the family to be able to ask these questions?’ The answers are likely to vary according to whether these are types of questions that are asked already as was the case for the children’s support programme. Are assessments often made independently of the family such as the case of the agency working with young people? The agency working with young people was not able to complete the assessments for those they had identified as having caring responsibilities. This was because the agency team felt that their relationships with young people would be compromised if they were to ask the questions, something we always knew might happen. The voluntary organisation that supported those with a specific disability does not make assessments, but works with members who request specific sorts of supports. Yet this was one agency that recognized the demands on the children in the families they supported by bringing children together for shared outings, although participation was not on the basis that the children were young carers and not all who were offered the opportunity chose to participate.

One of the challenges of using the tool was that it involved assessing caring within families that could have a lot of other concerns and issues to deal with. Using social agencies meant that families might be in crisis before they sought help. The tool tried to take account of this by asking for agencies to include contextual information. For example, when a new partner of a parent in one family spent time at home things got worse rather than better even though one might expect an extra adult in the house to improve support. The contextual information was useful, but at times it was impossible to differentiate factors associated with children taking on a caring role and other issues within the home. This was most noticeable when agencies tried to assess the impact of caring on the child, (e.g., how much emotional distress was caused by caring as opposed to a parent’s state of mental health). Likewise, the children had a large role in looking after themselves. When this care was inadequate, it is not the result of caring but rather not having another adult to provide that care. For example, two girls were taking responsibility for the cooking in the family, but they were not adequately feeding themselves. Understanding the child involves understanding the family. The challenge for developing the assessment tool is finding the balance between knowing the child(ren) as a carer, knowing the child(ren) in general and knowing the family. Certainly a needs assessment would have to take account of this dynamic.

Those filling in the forms were asked to make a judgement about the level of care being provided. In none of the cases shown above were families or children referred to a service because of children taking on a caring role. All the children identified were deemed to be taking on a level care that was beyond what might be expected of most other children. The threshold was set reasonably high and the one case that was referred but was not included was in the case where families were invited to submit their own assessment. It was in the cases where the children who were taking the sole responsibility for care that children were doing the most work, which for two of the children meant looking after young siblings. There is a balance however, in the profile for these two families the assessment showed that in each case the older child was taking most of the caring responsibility, including looking after a younger sibling, but at the same time was being supported by the younger sibling to carry out the caring tasks.

Most of the children identified were supporting another adult to provide care. This meant that while they had tasks to do they did not have the emotional responsibility of sole care. No doubt there are many children in this situation but their families have not required the support of one of the types of agencies that participated in this research. It is logical to think that there would still be a group of children with caring responsibilities within families that do not receive support from an agency. Alongside this group is another where adults reject external support leaving the responsibility for care with the children, as was one of the cases identified in this study. The reason that this case was identified by an agency was the parent was seeking (non-caring) support for his children rather than himself.

Other networking opportunities

A number of people have made contact with the researcher and the advisory group after hearing about the project. It is clear that others are also identifying the issue as a concern for research. An anthropology student as part of a Masters Thesis at the University of Otago has interviewed a group of adults who talked about their past as young carers (Loose, 2004). An MA student at AUT was looking at the role of art therapy for children of parents who have a mental illness where caring is one of the concerns that children have to deal with (Langston, 2004). One DHB has allocated funding for a single year to put in place a support worker for young carers. This growing interest should allow ongoing engagement with others to the point where more formal meetings and forums can be arranged. This growing interest, of which this project is a part, has also been supported by the media attention given to the case in Napier in 2003 (White, 2003).

In July 2004 Carers Society Otago ran a one-day seminar for those who we had established had an interest in young carers. The result was 10 people meeting to share the type of work that they had initiated. After the morning session the afternoon was used to discuss the current issues facing young carers and the agencies that work with them. As a result of the days work two articles appeared in a local newspaper (Vannisselroy, 2004a, 2004b).

Discussion

There were some similarities between the data collected in this research and the YCRG surveys conducted in the UK and summarised earlier in Table 1 above. For example, the average age of young carers in the UK surveys was twelve, whereas the median age in this study was eleven. Two thirds of the young carers in this study were female which was close to the 61 percent in the 1995 UK study. The ranking of the nature of the illness or impairment of the care recipient was the same: physical, mental, learning, sensory and then ‘other’. Like the UK study most of the caring involved domestic work with emotional support being important, whereas providing intimate care and childcare was less common. Unlike the UK study where it was usually the mother being cared for, in the current study the majority of those being cared for were fathers. The results about the type of care were similar to the Western Australian study (Murrow, 2005), when social agencies were asked to identify young carers. The results were different from a smaller group of young carers identified by a carer agency. In that part of the study a larger number of males were in the caring role, the majority of children were caring for siblings and the children were performing a lot more of the personal caring tasks, however in this part of the study it was not possible to tell if young carers were in a primary or secondary caring role.

One of the first things we learnt when working with social agencies to identify young carers was that families and children were not using the agencies because of the children’s caring role, but because of other family issues. The complication is that families and young people expect services to respond to the issues raised as part of a referral. Those working in the services express difficulty in broaching new areas until they had earned the trust of the families. Many of the families and young people are coming to the services with complex lives, nearing crisis or well into it and providing support involves working through complex problems. Family issues, in the first instance, are not necessarily resolved by addressing the concerns about the children’s caring role in the family. The outcome is that caring can remain hidden. So, assuming most children are not raising an immediate care and protection concern, agencies will then have to spend time building relationships and trust before they can make suggestions that there are other issues to be addressed beyond those that caused the initial referral. There may be agencies that are receiving referrals about the caring responsibilities of children and others in the family, but they were not part of this study.

Remembering that in two thirds of the families identified where the children took a support role as carer it might well be the case that a lot of the stress for the children can be alleviated by addressing the caring concerns for the primary carer in the family. Once again, a family based assessment would seem to be suggested. The barrier to this approach is that when families engage with agencies they do not actively ‘invite’ a holistic family assessment.

As a result of the complexity it can be quite difficult to make a judgement about the relative impact of the caring role on a young carer in comparison to other issues within the family. For example, in one case a child was truanting from school to take on some caring duties, but they were also truanting to do other things because there was no adult ensuring they get to school each day.

In a study completed last year of a small group of NZ adults talking about life when they were young carers it was apparent that families did not come to the attention of social services when there was only the single issue of children taking on a caring role (Loose, 2004). This suggests that many children in the role are not being identified even while the initial services to support the adults or siblings with impairment or illness are being put in place. The implication is that more of these children are likely to be identified and their needs met when the notion of client and the basis of assessment are extended to the whole family rather than an individual ‘client’ within the family. This is what Dearden and Becker (2001) are advocating. The UK Department of Health (2000) is promoting both a child centred assessment that adopts an ecological approach to understanding the child, the outcome however appears to shift the focus toward the child rather than the family. This is probably not surprising given the legislative focus that this work builds on (The Children Act). But maybe it is the focus on ‘children in need’ rather than ‘families in need’ that encourages people to be silent on the matters of children taking on caring responsibilities. A more family centred approach can be found within the Social Services Inspectorate document *A jigsaw of services: inspection of services to support disabled adults in their parenting role* (2000). “A clearer approach to service provision based on an assessment of the needs of all family members and how they inter-relate and impact on each other is needed” (p. 34). This work was based on eight inspections in four English councils. Within the councils inspected they found…

> that although, according to senior managers, the social model of disability guided the council’s work this did not follow through into their staff ’s actions. The focus of staff appeared to be either on the children in the family or on the impact of the adults’ disability on their personal needs. Workers rarely looked beyond this and seldom focused on the whole family and how to support and help the parents in the discharge of their parental duties in their social setting. (p. 2)

The feedback from disabled parents in the study was that social services staff should be “obtaining the views of all the family members… (and) continuing to discuss issues with family members as part of the review” (p. 18).

Those models of service delivery that might support such an approach come from the area of disability support and early intervention. Person centred planning has been developed within disability studies as a means of focusing programme delivery around what is meaningful for the care recipient (Holburn & Vietze, 2002) whereas family centred practice is based on widening the scope of who is the client to include the family. Family centred practice has developed from work with families with very young children (Dunst, 2002; Kaplan, 1986). The person centre planning appears to have been developed to support adults with disabilities in the community working from a strengths-based model (Holburn, Jacobson, Vietze, Schwartz & Sersen, 2000). The main feature of emerging ecological models is that they take account of all the relevant relationships that support a family (Wise, 2005). The result is a relationship-centred care developed within the discipline of Gerontology that acknowledges all people involved in caring should feel a sense of security, belonging, continuity, purpose, achievement and significance (Nolan, Grant, Keady & Lundh, 2003). The development of such models in relation to caring will mean that children will be taken account of within the family dynamics of caring.

The other feature of taking into account young carers’ relationships, as well as roles, is that it is evident those same children are still cared for by others, especially where the children are in the secondary caring role. Young carers and care recipients are capable of both caring and receiving care. Once the models of care start to acknowledge relationships and reciprocity, then assessments can be based around establishing a balance of care that supports the well-being of all family members. With this in mind, an important process indicator of the well-being of young carers are the ‘parenting relationships’ that young carers have. Most of the young carers in this study had someone who had a parenting relationship with them alongside of the person they were caring for. It was when the parenting side of relationships deteriorated that negative outcomes were likely to accumulate. Dearden and Becker (1998) use education as an outcome indicator of how young carers were doing and I would propose that the parenting relationship is a process indicator that will mediate such outcomes. In this study the one family that was not included because the child did not take on a significant caring role was a sole parent family where the parent was receiving support to parent alongside receiving other domestic support. Unlike domestic support where another person does the work instead of the care recipient, this parent had been able to receive, with difficulty, support to fulfil the parenting role and maintain the relationship, not replace the relationship. It becomes a question of how can ‘care recipients’ be supported to care as well as be cared for. This is in line with Dearden & Becker (2001) who said parents do not want their parenting relationship undermined. Researchers can now ask how supporting the parenting relationship reduces the stress for the young carer, not just in terms of tasks such as who is feeding the child or making sure they get to school, but also in terms of emotional support attached to these activities, such as taking an interest in what is happening at school. Intervention or the provision of support is then about moving from one balance of care to another that improves the well-being of all family members. Within this framework we can then try and understand how that balance is influenced by children taking on a primary caring role and whether that necessarily acts as a critical threshold of concern for young carers.

Understanding the caring dynamic in families as a balance where children take on a significant caring role will expand the concept of needs assessment. It will also provide a means of including those children who care for other siblings. This group was not evident in the young carers identified in this study, but was a group that was increasing in the YCRG surveys (Dearden & Becker, 2004).

Agency assessment

The variation in approaches to assessment by agencies, which is a reflection of the different types of work that they do, has implications for the way we encourage services to continue with the identification of young carers. The amount of family privacy associated with young carers means that there is no easy approach to identifying them. By raising the profile of young carers with the agencies that we worked with it was evident that in the past agency personnel were aware of children and young people taking on the role but it was not central to their assessments. By making the tool available to them and working with them to find a place within their assessment process it was possible to raise the profile of the young carer and this aspect of family life. If more of these children are being identified as a result then agencies will take this part of the children’s lives into account.

One of the assumptions to avoid is assuming that ‘extra’ or ‘significant’ caring is necessarily negative. Families may not identify the ‘extra’ caring that children do as a concern, because they realise it is not ideal, as Aldridge & Becker (1994) have shown. But also, it may not be identified because it is an accepted familial norm. The professionals working with families assess all the information about the family they can access, including the caring tasks and the mix of outcomes for the children due to caring and all the other relevant concerns in their lives. They must take account of whether it is the amount or types of tasks being undertaken, or the stress that caring is causing a young carer alongside other family concerns when deciding how to work with the family. Their aim will be to support the families to find a sustainable level of well-being where within the mix of outcomes children are not overly disadvantaged by their role as young carers. The thresholds to use as part of this consideration appear to be around whether the child is taking on a primary or secondary caring role.

The difficulty, for ongoing research, is identifying where children are taking on a significant caring role but they have not come to the attention of social agencies unless other factors push the family into crisis. Other means of identification, such as surveying schools, is another possible avenue. Even then it will take a large-scale survey to get an overall indication of numbers in the school community. This was not straightforward as some Australian researchers discovered (Carers Association of Australia, 1997). And on any particular day that a survey is conducted in school it could well be those in a primary caring role are absent. Where young carers are coming to the attention of agencies researchers should not expect them to compromise their relationships with families in order to collect data. This increases the chance that these children will remain hidden in a research context. In the UK the research of Young Carer Projects was only obtaining a 40 percent response rate to the survey asking for assessment data on young carers. There is no indication how or if the other 60 percent collect assessment data on the children who use their service.

The other challenge is getting assessments conducted consistently across agencies in terms of reliability. In the current study this was addressed by spending time with agency personnel to ensure they understood what we wanted. This was partly achieved by asking people to evaluate the format and questions of the assessment tool before it was used in order to adapt it for the agency. Even in the UK where assessments can be requested for carers, including children, there is no requirement that the 300 local authorities that have to provide the assessment conduct them in the same way that would then allow for the collation of data afterwards. In New Zealand there are few systems in place that would allow for the collation of information about young carers. One possibility would be the NASC assessment process. It was unfortunate that we were not able to include a NASC service in this study, but even they would face similar issues that the agencies in this study face. Do assessors have the trust of families to talk about what caring roles children in the family are taking on? Even if they have ‘permission’ to ask the questions does the assessment process and current social expectations make it acceptable for families to discuss such matters with needs assessors?

Even on those occasions when families’ needs are being catered for by an external agency that is providing support for a family member with an impairment or illness, there are other issues for young carers to be considered. This includes looking at the way professionals come into families’ lives. For example, how are children kept informed and involved in decision making given that some of the young carers are taking on a lot of responsibility in the home and have a good understanding about what forms of support may or may not work. This type of information was not collected as part of this project but it would provide a useful perspective on support satisfaction and on what types of interventions families, including children, would like (Social Services Inspectorate, 2000).

Challenges

The use of the term ‘young carer’ and ‘care recipient’ does not encourage an ecological understanding of the family based on reciprocal relationships and interdependencies. Focusing on interdependencies would seem to be supported by a broader family assessment rather than assessing individuals independently. While individuals within the family will want to make sure their concerns have been heard, including children, there has to be some co-ordination of the assessment in order to get some integration of service. Indeed much of the confusion around assessment disappears if one acknowledges that while an individual within the family has an impairment or illness the result is the family experiences the disability alongside the impaired or ill person who is ‘disabled’.

The limitation of working with social agencies is that children whose main and only concern is caring for another family member will not come to the attention of these agencies. Whereas, in this study it was the children who were caring in families where there were multiple problems that came to their attention. The types of agencies who participated in this study would tend to see families with more complex difficulties and very few families coming forward where the only concern is children in the role of carer. It would suggest that, rather than only conducting the research at the extremes of family functioning, a survey of children and young people’s lives across the spectrum of family functioning would be useful. This might be achievable in a general survey of children’s lives where a small number of questions are included to establish the range of domestic and caring routines that children undertake.

Conclusion

This research has made a start in the work of identifying young carers in New Zealand, but the issues raised by the work provides more challenges than solutions for those who work with this group of children. Since this research began a national network has been put in place under auspices of Carers New Zealand. It is Young Carers New Zealand, which has had support and recognition from the Office of the Commissioner for Children and Children, Young Persons and their Families.

Recommendations

It is recommended that:

A survey is conducted to determine the current range of domestic and caring roles that children in general undertake within NZ families. This can create a benchmark against which to evaluate the number of children who have a primary or secondary caring role for others in their family. A survey would also give an indication how many children are taking on more significant caring tasks or roles. It is not necessary, and possibly preferable, that this not be a stand-alone survey of children's caring roles but part of a broader survey of children's lives in NZ.

The Ministry of Health and Carers New Zealand continue to work together to raise the profile of young carers with social service agencies so as to remind them to consider this dimension of children's lives. This would include specific mention of young carers being made in new government strategies, policies and legislation relevant to carers. The diversity of approaches adopted by agencies in respect to their assessment and intervention processes means that the tool as developed as part of this research cannot be implemented as is. Instead agencies have to be given the opportunity, or challenged, to reflect upon their assessment and intervention processes so that space can be found to include some consideration of children's domestic and caring routines at home.

That the relevant government agencies and non-government organisations responsible for the well-being of young carers engage with and formally support Young Carers New Zealand, which has been set up as a special interest group under the auspices of Carers New Zealand. **This is to insure there is a viable national voice for this invisible community of family caregivers.** In this way key government bodies that have frequent contact with young carers (education, health, ACC, WINZ, CYF, etc) can be active partners with Young Carers NZ to support its development.

In those families where children do have a caring role and various supports are put in place, such as occurs as part of a NASC assessment, then **an evaluation is conducted to determine the impact of interventions on young carers to indicate what challenges children face even when the family member with disability or illness is supported**.

While there is some value in 'creating' the term 'young carers' to promote discussion and increase their visibility, in the end meeting their needs should occur alongside supporting the whole family. **More conceptual work must be done to establish the most useful means of engaging with families whereby everybody's needs are considered during the assessment and intervention processes that follow**.

Because of the complexity of some young carers lives, as identified by the agencies in this research, **that case study research involving children, parents and whānau and agencies are included to provide a more complete picture of family life involving young carers. This would also include research into the outcomes for young carers as they make the transition to adulthood, including employment and tertiary education.**

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Appendix One

Children's caring and domestic role at home

Service Identifier:

Age and gender of children in the home

Age	DOB	Male/Female
Age	DOB	Male/Female
Age	DOB	Male/Female

Cultural Background (Please circle or specify)

European Maori (Please Specify Iwi) ______________

Pacific Island (Please specify) ________________

Other (Please specify) ____

Other Household Information

Who lives in this household? eg. Other adults, other children, extended family. (It may be useful to draw a 'family tree' on the back to show the structure of families within the household and any variations across the week)

Generally we find that caring and domestic responsibilities change when there is a person with a disability in the household. Is there a person in your household/family with an acknowledged disability/ impairment/ illness? (Please describe the disability etc and how long it has been present or significant. What is the child's/children's relationship to this person?)

Reason(s) for referral to agency:

This information has been filled in by:

Table 1: Role within household for family in general (rather than for specific people – see Table 2)

- **Main role in family** – Is solely (but may be with other children) or jointly responsible for doing these things.
- **Support role in family** – care given but in support of primary caregiver or in the absence of primary caregiver

If there is more than one child involved record as for the child doing the most of the work under that task category.

Decide if the child is taking the main role or support role – see two columns in table below. Describe which tasks are done and how often they are done in the appropriate box below.

	Main role in family	Support role in family	Use (DK) when don't know	
Caring Tasks	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do any of these	Who else is involved in doing these tasks?
Household Care/domestic tasks for household in general. eg. Cleaning, washing, Vacuuming, looking after pets, cooking, shopping, outdoor chores, responding to mail and phone				
Childcare eg. Providing care and doing specific tasks for siblings, parenting tasks				
Financial eg. Working so as to support the family financially, attending to finances and budgeting,				

Table 2: Care for other(s) in household

Decide if child is taking the main role or support role. Describe tasks in the appropriate box indicating how often they are done.

	Main role in family	Support role in family	Use (DK) when don't know	
Caring Tasks	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do any of these tasks	Who else is involved in doing these tasks?
Personal/Intimate Care eg. Showering, dressing, assisting with eating, Toileting				
Emotional Support eg. Comforting, listening, advising, decision making, negotiating				
Medical Care eg helping to administer medication, attending appointments, going to chemist, communicating concerns to professionals				
Social Support eg. Going out on outings, social activities, helping with mobility, arranging visits				
Financial eg. shopping and paying for particular items, paying bills for this person				

Table 3: Which care and domestic routines does the child (or children) do for themselves

Decide if child is taking the main role or support role. Describe tasks in the appropriate box indicating how often they are done.

	Main role in family	Support role in family	Use (DK) when don't know	
Caring Tasks	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do any of these tasks	Who else is involved in doing these tasks?
Providing care and doing specific tasks for themselves eg any of the tasks listed in the previous tables. *Personal Care* *Emotional Support* *Medical Care* *Social Support* *Financial Support*				
Who are providing the parenting for children in this household?				

Table 4: Other care and domestic tasks not described above – this may include caring for others outside the household

Decide if child is taking main role or support role. Describe tasks in the appropriate box indicating how often they are done.

	Main role in family	Support role in family	Use (DK) when don't know	
Caring Tasks	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Describe tasks Note how often they are done (eg, daily, weekly and monthly or always, often, and sometimes etc)	Doesn't do this task	Who does do this task?
Please list others if any				

Please make any other comments to help us understand the general level of acceptability for this child (children) and the level of responsibility and the amount of care or work undertaken. This might include also referring to others also contributing to tasks within the household. Please note any comments/attitudes made through the interviews.

Table 5: The advantages and disadvantages of the caring role for the child or children

How does the domestic and caring role advantage and disadvantage the child in regards to?

	COMMENTS
Physical Health eg. Tired, rundown or self abuse, often unwell	
Emotional and Mental Well-being eg. Indecisive, anxious, depressed, negative behaviours, takes a lot of responsibility for family, feelings of guilt, anger or resentment, embarrassment, mature for age	
Social Participation *eg. Are they unable to participate in out of school activities such as clubs or sports*	
Relationship with peers eg. They may prefer the company of older people because of responsibilities, they may be embarrassed about their home life. May not have opportunities to build friendships.	
Education eg. School non-attendance or truancy, unable to focus on working toward qualifications	
Relationships within the household eg. Strained relationships with adults or siblings or the development of dependent relationships that would not be expected for most children.	
Employment eg. Less able to take on part-time work compared to other young people their age.	
Transition into Adulthood eg. Denial of past, youth offending, restrictions on developing independence – in terms of finances, living arrangements, employment/tertiary study.	

How does the family or family members benefit from the child taking on the domestic and caring role? Who within the household, if anyone, benefits the most?

What is the child’s perspective on their role in supporting the family by taking on a domestic and caring role?

Table 6: The current domestic needs of the family and child (or children) and the supports in place

	COMMENTS
Does the level of work and type of care being provided by children suggest that domestic support is needed? Yes/ No. If yes have others recognised the children(s) contribution to this household? Yes/ No.	If yes, who and if applicable what forms of support do they provide? If not mentioned already, who is providing a lot of the general care for the child or children?
Are all the child's/household's domestic and caring needs being met as well as might be expected in this household? Yes/ No	If no, what are the household's (or child's) current or impending unmet needs?
Are you in a position to see that these needs (or some of them) can be met or refer them on to those who can? Yes / No	If yes, which needs can you respond to? If no, who will you refer on to?

Please record (turn over) any other features of this household/family that will help us understand what is happening for the child or children.

Appendix Two

Profiles of the agencies that contributed to the research.

Family social service agency

Background

Families come to the agency either via self-referral or referred by other social agencies. The main reason that agencies make the referrals is because they think that parenting in the family could be supported to be more effective. That said, self-referrals make up half the clients that come to the service. With the focus being on parenting and child behaviour the families generally have children who are younger than twelve/thirteen. The agencies making the most referrals are Child, Youth & Family, Public Health Nurses and Plunket who all refer just over 10% each. The length of time families engage with the service varies with one third for 1-2 months, one third for 3-4 months and one third for 5-12 months. The service tends not to take on families in crisis or that need financial support as they use other agencies. A significant amount of the work involves family advocacy, including working with other agencies in the community. This includes helping families work through government agency processes such as Work and Income New Zealand, Inland Revenue Department, Child, Youth & Family and the local District Health Board. The advocacy can be direct or as extra support. The referrals are voluntary except those that might result from a CYF process such as a family group conference.

Very few of the families could be said to be single issue families such that a social worker could identify a simple cause and effect. The majority of families who come are quite ‘complex’ and bring with them ‘complex problems’. There is usually a threshold of ‘discomfort’ that a family must reach before they would consider using the service, which means that ‘family life could be quite destructive’ by then or on a ‘negative path’. Families have differing ideas of privacy and about what it means to disclose ‘dirty linen’. There are fewer ‘professional’ families using the service and those who do tend to be more suspicious about the service and ask more questions. These factors indicate varied perspectives that parents have about the agency and its role, notions of independence, and the acceptability of seeking the type of family support that this service offers. So families tend to have a lower class background, are often beneficiaries and it is the women rather than men who are the contact for the family. This collection of factors also means that many of the clients are from single parent families.

Assessment

Tied up with the process of getting to know a family is the referral and assessment process. The adults in the families identify what they want to work on – or what they consider to be the problem. These may change over time. In relation to this research then, is how children taking on caring responsibilities might be positioned in relation to families dealing with problems.

In general a starting point for developing the service- client relationship is based on asking what the family would like to be doing better. There is a premise that clients will be honest in raising concerns. Initial areas of concern raised by parents are child behaviour, family relationships, financial pressures and justice system issues. The primary contact is usually the mother in the family. Ninety percent of cases involve a home visit, but social workers tend not to work directly with children. The aim is that if there is to be a lasting change in child behaviour it should be initiated by the parents supported by the service.

The families that use the service are not in immediate crisis: those families are referred elsewhere. There are differing understandings about what might be described as a successful outcome for a family as a result of using the service. It may not be a matter of dealing with issues directly, but about giving parents a sense of agency so that they feel they can deal with problems as they arise, without further external help. Social workers can often predict which families they will see again. This means that what is judged as a successful outcome for one family may not be judged as successful for the next family.

How the service might use the tool

As the service operates an open file approach to record keeping their preference is for filling out any forms with the family. Much of the work for the researchers involved adapting the data collection ‘tool’ so that it would fit this approach used by the service. A number of issues arose from this process.

The tool was initially very deficit orientated and the title ‘identifying young carers’ did not indicate why this would be an important topic for researchers or it could possibly imply that to be a young carer is negative (even after explaining in more detail what the research was about). There was a definite focus within the tool around disability. For many families this was not necessarily an acknowledged issue (even if it was present). Because the service operated on responding to family concerns using the tool would place social workers in the position of having to raise issues that had not been offered up by the families as an area of focus for the social worker. If this had been the case the social workers would prefer to refer potential participating families to the researchers to ask the questions.

The tool was modified so that it no longer referred to young carers, but used the term ‘caring and domestic responsibilities of children’. Disability could be a factor that impacts on the responsibilities of children but not a necessary or acknowledged one. The order of questions was changed so that it asked the general ones first through to the specific with the aim of identifying areas where children have responsibilities before asking the questions that might imply that this could be a cause for concern. The impact of the work is now viewed as ‘possible advantages and disadvantages’ of children taking on a caring role.

Their experience with the tool

The modifications to the tool made it more acceptable when filling it alongside clients. In the year that the agency spent looking for young carers they identified 2 out of 130 families who used the service.

In its limited use it was found difficult to get the tool’s frames of reference to match the families who use the service. That said, a social worker said it was easier to understand the tool when filling it out with the researcher to explain each question.

Specific comments noted were that Table 5 and 6 in the tool oversimplified family problems and suggested that the only issue would be around a child taking on caring responsibilities. The implication is that the provision of support for the caring responsibilities will lead to better outcomes; cause and effect, without taking account of other issues. Table 5 (How does the domestic and caring role advantage and disadvantage the child in regards to?) implied that the researcher only wanted to know about child outcomes that were attributable to the caring role rather than other issues that are also present. This would be very difficult to ascertain, if not impossible, given that most families come to the service with multiple issues/problems to work on. Table 6 (The current domestic needs of the family and child (or children) and the supports in place) also asks the social worker to identify within the family only those issues and types of support that link to the caring responsibility as though it was possible to separate out the concerns that relate to caring as opposed to other issues.

Children’s Support Programme

Background

This programme provides support in the form of an adult friendship for children with a carefully selected, trained and supported adult volunteer. The friend can provide support, guidance and model alternative ways of dealing with the world, but they are not expected to take on the role of counsellor or substitute parent. The programme does not attempt to respond directly to the needs of the families or any associated outcomes for the children. Some of the Children are in families where parents are stressed and tired with their own problems, lack the social resources to deal with them and the children will sometimes take on the emotional or financial problems of their parents. The relationship gives children the opportunity to spend 2-3 hours a week with an adult doing ordinary activities at the same time as developing a relationship that will be extended over time. One of the outcomes of the programme is to improve the self-esteem of the children.

Referrals are from agencies that come into contact with families and the children or the families may make referrals themselves. Matching children with adults is an important part of the programme and the friendships last for at least 12 months many last longer depending on situations.

Assessment

Referrals to the programme are for children 4 to 12 years old. Assessment includes asking questions about whether the child wants to participate? Will they be able to develop a relationship with someone outside the family and what does the parent want from the programme? What supports are they receiving elsewhere and are their levels of need appropriate to the people they are matched with? Will the programme make a difference for the child?

Once an assessment is made and they are deemed to be children who can benefit from the programme then children go onto a waiting list until an appropriate adult is identified. Assessments include interviewing both parents and children separately. Children are asked, “Do you have chores that you have to do at home?” and “What do you do after school and at the weekend?” Parents are asked, “Is there anyone in the family with health problems?” and “What are the child’s responsibilities at home?” Thus the assessment process adopted by the programme includes a number of questions that might indicate whether children have a significant caring role in the home. Most of the assessment is conducted as part of deciding whether children will benefit from the programme when a family would usually be visited twice. After this there is a monthly checking of progress by the programme co-ordinators, but it does not involve reusing initial assessment tools.

How the service might use the tool

It was decided that a positive response to some of the programmes assessment questions would be used as a trigger to ask questions from the young carers tool. This means that the young carers tool only needs to be used if the support programme assessment indicates that the children have a significant role in caring.

There were very few changes to the tool made. A note was added on the front page to indicate whether the child was put into the programme waiting list or not as a result of the programme assessment.

Their experience with the tool

The filling out of the assessment tool was relatively straightforward as an add-on to the overall assessment process. It was clear, however, that as assessments were conducted early in the relationship and that assessments were collecting information that was not being used for direct intervention purposes that some questions were difficult to answer. It was relatively easy to identify what the children were doing as tasks within the home but it was more difficult to ascertain the impact on the children of undertaking the caring tasks. It was also difficult to answer the question on the children’s perspective of their caring role without more prolonged contact with the family. In some cases the assessments were not reviewed until a number of visits had been made with the family and programme workers had got to know the families better.

Voluntary support organisation

Background

The agency is a non-profit organization directed by volunteers via a committee at the local level with an affiliation to a national organization. The agency provides various forms of support and assistance in the wider local area of Otago to those with a specific 'disability'. The agency employs a fieldworker to provide counseling and advocacy for members. About a third of members had children in the 0-18 age group.

Assessment

There is no formal assessment process in place. The societies members choose which services to receive (eg a newsletter) and decide if they want support from the field worker. For this reason the field worker said it was not her role to elicit information from members in the same way that other services might. However, the agency did recognize that children in the families that they supported also had separate needs, which they responded by bringing the children together for outings. About a quarter of the families in Dunedin with children of the right age group had children attend the group. This group formed a major part of those that were invited to come and hear about the research.

How the service might use the tool

The field worker was happy to distribute the 'questionnaire' on our behalf, but as we were in the trial phase we decided to ask members to come to a meeting with us so that we could introduce the tool to them and take them through what we were looking for. This was not our original intention for the assessment tool, but given that there are a number of agencies that are organized in the same way, we thought it might be useful to see how people responded. The title of the assessment tool was changed from *Children's caring and domestic role at home* to *Children's roles in the home with a parent with a disability* to indicate the link between the agency and the purpose of the assessment tool, which is found to be very broad in its title. We also changed the questions *How does the family or family members benefit from the child taking on the domestic and caring role? Who within the household, if anyone, benefits the most?* To *With the child or children taking on these domestic and caring tasks within the home how does this contribute to daily family life compared to if the child was doing fewer of the tasks or none at all*? This was done to avoid the possible interpretation that asking about how families benefit from children caring may be interpreted as us asking about exploitation of children. Instead we wanted to been seen to be asking parents how their children make a positive contribution to the family. The wider the possible audience for a 'questionnaire' the more such 'mis'-interpretations need to be considered.

Their experience with the tool

A dozen people came to a meeting at 5:30 in the evening. There were some teenage children also present. We reviewed what we as researchers were looking for and left people with the tool to complete and send back via a post paid envelope. We received two returns. The returns from parents indicated that the children did not take on more caring and domestic tasks than might be expected of at their age, but the children were aware of their parent's physical impairment and the challenges they faced at home.

We found the assessment tool encouraged people to place ticks in columns rather than write comments, which is not what was desired. The form was altered to avoid the impression of 'lots of boxes' on the page for ticking.

Young Persons' social service agency

Background

For this agency the primary focus is the young person, however this focus is flexible to fit with the cultural needs of the family. The large majority of the referrals come from schools, social agencies and families. This means that the caseworkers have to spend time developing the relationship, which is the key therapeutic tool in working with the young person and their family. The issues for young people often relate to mental illness, alcohol and drugs, behavioural and school setting problems, including truancy.

Assessment

The service conducts a comprehensive assessment to collect information prior to assigning a social worker. The initial assessment involves 'youth self report' which explores the young persons perspective on their current situation. Alongside this information is gathered from the young person's guardian, parent or other 'responsible' adults as well as their educational setting and other involved agencies. The assessment includes a question on what jobs or chores the young person has in the home. After assignment self-report measures are used to monitor progress.

How the service might use the tool

As with other agencies the main concern is when to ask someone if they would like to participate in the study, but it is also a question of who should be involved. The key principle is that working through this should not compromise the relationship between the caseworker and the young person. The caseworkers have to make the judgement about when to move on this, if at all.

A major understanding reached by participants and researchers is that the researchers do not want caseworkers to operate outside their own ethical boundaries. In discussion it was agreed that young people would give their consent to participate (by signing the tool) but given that the ongoing relationship with the family is a critical factor to be considered it was agreed that where appropriate parents would be told that their children would be talking with the caseworkers about the domestic and care routines at home. If a parent or caregiver shows some interest they could be invited to contribute to filling in the tool and then they would sign it at the same time as the young person.

Table 5 includes examples of what the researchers might be looking for on a particular question. These examples were removed so that the caseworker could contextualize each question based on what they knew of the young person and how sensitive they might be about particular topics.

One of the differences between this service's caseworkers filling in this survey and other service staff is that case workers are doing it for the young person they are working with. In other services staff fill it out for the whole family. The tool is very much set up with a professional assessing the family. To recognize this we made space available on the front page to acknowledge who participated in filling out the form. The case workers also said they may acknowledge information, which is in dispute or unknown. For research this raises the question about acknowledging whose views are being recorded as data.

This gets complicated when there are other siblings involved in providing a level of care. Where possible if the young person does indicate that other siblings are involved then the caseworker will attempt to collect the information about who else is providing care. This is done on the basis that we wish to understand the relative contribution that the young person makes compared to others in the family. Ethically, while we are collecting information about other people, we are doing this in relation to the person who has the relationship with the service and it is acknowledged that it reflects this person perspective, rather than us wanting to validate data, which might require us talking with others in the family.

Their experience with the tool

The caseworkers identified young people who they felt were in the role of young carers but there were none that they felt were in a position to participate in the study by collecting the information. The caseworkers had a total of 80 cases of which they believed that 9 would probably meet the criteria for participation in the study. This is an unconfirmed identification rate of 11 percent. On the basis that the service has a caseload of 374 over the year then 11 percent would represent a figure of 40 cases involving young carers.

The reasons for referral include:

Truancy	8
Family factors	5
Mental health	1
Educational issues	1
Transition to high school	1

The number of reasons for referral is higher than the nine young people identified as multiple reasons were given on some referrals. Only one case included a referral that included a concern about the caring role that the young person had within the family.