

**LITERATURE REVIEW OF IDENTIFICATION, NEEDS
ASSESSMENT AND SERVICE PROVISION FOR
YOUNG CARERS AND THEIR FAMILIES**

**Pauline Banks, Eamonn Gallagher, Malcolm Hill
and Sheila Riddell
Centre for the Child and Society
and Strathclyde Centre for Disability Research
University of Glasgow**

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EXECUTIVE SUMMARY

The Study

The objectives of the study were:

- examine the ways in which young carers come to the attention of voluntary and statutory agencies, and factors inhibiting identification
- identify the ways in which young carers' needs are assessed
- examine approaches to service provision by both statutory and voluntary agencies
- identify approaches that are successful in meeting the social, educational and health needs of young carers
- assess the results of any evaluations of the ways in which services are delivered.

The primary element of the research was a **literature review**, focusing on published work. This was supplemented by:

- a **questionnaire survey** of local authorities, health services and relevant voluntary agencies in Scotland
- **analysis of documents** provided by those agencies
- **interviews** with a small number of experts (11)

The scope of the study was limited by the time available for carrying it out (2 months). Where possible, the review focussed on documents relating to young carers' issues in Scotland. Inevitably, however, many of the documents reviewed were concerned with carers' issues across the UK and the review concentrated primarily on UK rather than international publications.

Overall observations on previous research and literature

With few exceptions, the literature on young carers has focused on children who assume caring responsibilities with respect to parents, and much less is known about those who assist with the care of siblings, other relatives or non-relatives.

The main topics covered in the literature are:

- arguments for and against the conceptualisation of children who assist with the practical and emotional care of family members as 'young carer'
- research on the experiences and needs of young carers
- discussion of legal entitlements
- advocacy of particular policy and service responses to young caring
- descriptions of service developments, mainly specific young carer projects

Definitions and legal duties

The concept of young carer was initially developed largely in relation to children with a parent who has a physical impairment. In such families the 'young carer' undertakes 'significant' personal care tasks towards the parent and/or carries out other household activities that the parent is not able to do. In keeping with the widening concept of disability in legislation, young caring has been extended to encompass circumstances where parents

have a range of issues – physical impairment, chronic or terminal illness, mental health problems and dependency on alcohol or drugs. It has also been recognised that children may take on a caring role with respect to other family members, particularly their brothers, sisters or grandparents. At the same time, it has been recognised (as in the Children (Scotland) Act 1995) that children may need help because they are adversely affected by disability in the family, although this may not entail caring in the sense of looking after someone or the household.

Most definitions recognise that both ‘caring’ and ‘adverse effects’ occur along a continuum. A crucial distinction is often made between a *sole or primary carer* (where the child is the only carer as no adult is available) and *supportive or secondary carer* (where the child assists an adult). When a child is caring for a sibling, this is nearly always in a supportive role.

A survey of over 2000 young people attending young carers projects found that rather more were girls (57%) than boys (43%) and just over half (54%) lived in lone parent households. Many were aged under 12.

Some writers and certain of our interviewees have challenged either the basis or the usefulness of the concept of young carers. They argue that it undervalues and subverts parental roles and diverts attention from the need to support parents so that children do not have to perform personal assistance tasks.

The legal duties of local authorities to young carers are contained in legislation related to disability, community care and children. This has led to some anomalies and uncertainty related to definition, assessment and service provision. However, the Community care and Health (Scotland) Act 2002 seeks to clarify the position on assessment.

Identification processes

The ways in which agencies identify young carers is affected by the complexities of definition outlined in the previous section. The notion of ‘young carers’ is not one that came from children themselves, but was created by certain adults who were concerned on behalf of children. Similarly, children and young people have not expressed a demand for services, so active processes are required to identify and locate them. The willingness of children to attend young carer projects indicates that they do accept they have needs to be met, which may be recreational, social or emotional. On the other hand, evidence indicates that most do not like the term or identity of ‘young carer’.

Agencies may identify *populations of young carers* (in order to plan or improve services) or *individual young carers* to assess their needs and perhaps encourage them to take up a service on offer. Aggregate identification is hampered by definitional difficulties and the varied forms in which agencies hold relevant statistics.

Little is known about how young carers come to the attention of local authorities. The literature includes many statements that adult services tend not to notice or heed children's needs, while children's services usually get involved in extreme cases, where there are child protection concerns. Young carers' Projects usually attract children initially by promoting awareness of the service among social workers, health professionals and teachers. The agency survey showed that, once established, the majority of projects receive self-referrals and referrals by parents.

Both the literature and the survey indicated that a number of Projects have difficulties in acquiring a large number of referrals, which is attributed in part to parents' unwillingness to give consent on account of various inhibiting factors. Research has indicated that children and/or their parents are often reluctant to seek help for a variety of reasons, including a wish for privacy, feelings of stigma and fears about community or professional responses. Others are simply unaware they may get help. It has also been suggested that identification of young carers is inhibited by ignorance among professionals in contact with the families and the views of some professionals that young caring is outside their remit.

Needs assessment

Young carers research and feedback from young people attending Projects has indicated that they have four main needs. These are for:

- information (e.g. about their parent's condition, services)
- individual support or counselling
- practical assistance
- social contacts and recreation

The disability rights perspective, in contrast, emphasises that the main need is to prevent or stop young caring by means of financial, practical and other support to the whole family.

Holistic assessment frameworks have been advocated for use by statutory and voluntary agencies. These promote integrated attention to the child, parenting capacity and the wider environment.

Children living in Scotland who are 'adversely affected' by disability may be assessed as children in need. From September 2002, they will be entitled to request their own assessment under community care legislation. Evidence from England indicates that few young carers (perhaps 10% of those identified by projects) have independent assessments of their needs carried out by local authorities. When this does happen, the children do not usually have a good understanding of the purpose of the assessments, but positive help to the family sometimes results.

Research on sole or primary young carers indicates that not uncommonly their school attendance or performance is affected by their caring role, but there is little evidence of concerted efforts by education authorities or schools to tackle this.

Referral procedures to many Projects are informal and brief, though some have extensive and standard formats. A minority of Projects have developed a protocol for assessment with their local authority. Several use pictorial questionnaire booklets or other tools to aid identification and joint assessment with young people. It appears that, at least in some cases, assessments are service led (i.e. to assess suitability for attendance at a Project) rather than needs led.

Service approaches

In the 1990s, service development was largely based on the principle that children and young people needed and were entitled to have access to a separate, dedicated service away from

home. This was sometimes supplemented by support to parents and advocacy. Recently attempts have begun to shift the focus to an integrated ‘whole family’ approach.

Most information is available about young carers projects, the great majority of which are provided by voluntary organisations. A few are one-off projects developed to meet local needs, but most are run by larger organisations concerned with children, disability or mental health. These include the Princes Royal Trust, National Children’s Homes, Barnardo’s, the Children’s Society and Crossroads. Many Projects have developed in response to local initiatives, so their availability is piecemeal. Few have long-term funding. Access and transport is a significant issue, especially in rural areas. Whereas some Projects in England are well-established, most in Scotland were set up very recently.

Projects normally focus on children and young people, though a minority also involve parents. Some are *generic*, in that the young caring of service users may arise for any of several reasons or might relate to any household member. Others are *specialist*, concentrating on particular circumstances, such as children with parents who have a mental health problem or misuse alcohol, or those caring for siblings. Age and other criteria for admission vary widely. Some Projects offer places indefinitely, while others have time limits.

Projects typically provide three kinds of intervention:

- group activities and discussions
- individual counselling or befriending
- advocacy on behalf of the child or family

The majority appear to concentrate on providing opportunities for enjoyable interaction with peers. This can serve as a trust-building basis for access to individual counselling.

Much less information was available in the literature and from the survey about the nature of local authority and health service provision. Evidently the statutory services are sometimes providing services to parents with care needs and the availability of these services will impinge on their children. Commentators have pointed out that inadequate support for parents who are chronically ill or disabled helps create or sustain young caring. Views differ on whether devoting resources to young carers projects is a necessary response to what is perceived as the inevitable shortfall in support to adults or contributes to that deficiency by diverting attention and money. Some local authorities and health services provide funding for young carers projects and individual professionals refer children to the projects. Also a small number have appointed staff or set up their own Projects with a focus on young carers. Direct payments have considerable potential to alleviate the circumstances of families with young carers, but little is known about their impact on children.

Co-operation between agencies has grown, but is still thought by many people to be inadequate. At a national level, young carers projects share ideas through their own network and the Carers National Forum, while at local level some joint initiatives have developed.

Evidence about success

Apart from feedback by service users, little evidence exists about the effectiveness of services that support young carers and their families. A few short-term evaluations of particular

projects have been carried out, either internally or by the Young Carers Research Group. Studies have examined satisfaction by key stakeholders, but not assessed outcomes or compared different strategies. Similarly no evidence appears to be available about the impact on young carers of interventions which aim at supporting their parents or siblings.

Young carers projects are generally successful in attracting children and young people, many of whom value the social and recreational activities. Some young people also report how helpful it is to have an independent person they can share their concerns with. Two evaluations in England indicated that planning and service development included little participation by young people, although an audit by NCH in Lanarkshire found that young people's views were obtained and seriously attended to. Several Scottish reports of service user feedback highlight young people's gains in friendships and reduced stress.

Conclusions

There is broad agreement that it is inappropriate for children to assume major responsibility for personal and emotional care or domestic duties, when their parents' capacities to undertake these are restricted. Actual and advocated policy and service responses to situations where this occurs are contested, however. Different approaches entail targeting parents, children and young people, the family as a whole or combinations of these. The differences reflect fundamental divergences in view about such matters as the nature of childhood, families, disability, mental health problems and rights, though some attempts are underway to establish common ground.

The main service development has been the development of projects which mainly offer individual and group activities and support for children and young people outside the home. These are generally enjoyed and valued by the young people who attend, but many young carers have no project near to them, resulting in geographical inequity of access. The continuing existence of many young carers indicates that financial, practical and other services for adults with disabilities or other difficulties are inadequate. There is a lack of co-ordination between voluntary and statutory agencies. Within the latter there appears to poor liaison between adult and children's services and limited co-operation between the various kinds of professionals involved.

Services for young carers are a prime example of the need for concerted efforts by different agencies and professions to develop a shared approach and provide coherent services based on holistic assessments, as promoted by the Department of Health *Assessment Framework* and the Scottish Executive *Action Plan*. It seems desirable to have a common strategy at central and local government levels in Scotland to promote a well co-ordinated programme of interventions aimed at reducing the need for children to be sole or major carers, while ensuring that children do have access to separate, confidential support where this is required.

Research is necessary to identify more clearly the spectrum of caring responsibilities undertaken by children within families covering households with and without a parent or child who has a disability. There is also a need for independent evaluations of assessment processes and service provision. It is important to assess the impact of measures such as Direct Payments and practical and respite services for disabled adults and children.

CHAPTER 1: INTRODUCTION

Introduction

During the 1990s young carers became identified as a significant group of people in need of support from social care services. They represent part of a wider group of children and young people affected by disability in their families. The threshold between those with and without major caring responsibilities is not clear cut, while the degree to which domestic and caring tasks are shared with other adults and children in the family is quite variable (Banks et al forthcoming).

In addition, there have been challenges to the concept of young carers from those who believe that the ‘young carers industry’ has distracted attention from disabled parents in need of services. Rather than supporting children and young people in carrying out inappropriate tasks, it is suggested that there should be a new emphasis on inter-dependence within families, so that services are delivered to meet the needs of both adults and children. Sometimes, these disputes have been described in terms of fundamental tensions between children’s rights and a disability rights perspectives. In this introduction to the review of the literature, we first summarise the aims and objectives of the literature review, then summarise the legal background underpinning the rights of young carers and subsequently, we describe the methods employed in the present review.

Aims and objectives

The Scottish Executive commissioned this literature review. The overall aim was to provide a comprehensive summary of existing knowledge of how young carers are identified and how their needs are assessed and met. Therefore the review largely concentrated on the interaction between young carers and their families on the one hand and service agencies on the other. Understanding the needs of young carers was an important context for the review, but was not the primary focus.

The specific objectives were to:

- examine the ways in which young carers come to the attention of voluntary and statutory agencies, and factors inhibiting identification
- identify the ways in which young carers’ needs are assessed
- examine approaches to service provision by both statutory and voluntary agencies
- identify approaches that are successful in meeting the social, educational and health needs of young carers
- assess the results of any evaluations of the ways in which services are delivered.

POLICY AND LEGISLATIVE UNDERPINNING OF THE RIGHTS OF YOUNG CARERS IN SCOTLAND

In the 1990s, a dramatic transformation took place in awareness and perceptions about children assisting disabled parents and other family members. They came to be known as ‘young carers’, reflecting the wider trend towards raising the profile of informal carers. Within ten years young carers moved from being hidden and in need of a service to being a prominent group in policy documents and actively sought out by a significant but patchily available set of services set up to identify them and cater for

their needs. The initial impetus for this development came largely from researchers and voluntary organisations. Both statute and statutory provision responded, with the carers' strategies of the UK Government and Scottish Executive including a specific focus on young carers. However, opinions remain divided on how best to assist young carers and even whether this is a useful term (Olsen 2000; Banks et al 2001).

Current legislation in Scotland seeks to ensure that young carers have a right to assessment of needs, a right to provision of services to meet these needs and a right to express their views about important decisions affecting themselves and their families. Young carers' rights and the duties of local authorities are dealt with through both carers legislation and children's legislation. In addition, disabled adults have rights to assessment and service provision which should take account of their responsibilities as parents. In the following paragraphs, we summarise the legislative underpinning of young carers rights, drawing extensively on the work of Professor Kathleen Marshall.

Section 8 of the Disabled Persons (Services, Consultation and Representation) Act 1986 states that a local authority, when deciding upon a disabled person's need for services, must take the carer's ability to care into account. The Carers (Recognition and Services) Act 1995 was intended to give all young people a right to an assessment of their ability to provide care. The results of that assessment should be taken into account when the local authority is deciding to provide care. Scottish Office guidance on the implementation of this Act said that young carers under the age of 16 had no such right because they did not possess the legal capacity to ask for an assessment. This anomaly is being ironed out by the Community Care and Health (Scotland) Act, which was passed by the Scottish Parliament in February 2002 and comes into effect later this year. In future, Scottish young carers under the age of 16 will be able to request an assessment independently of the cared for person. However, the Scottish legislation allows for support and resources, to be provided for carers. This support would take the form of either community care services to the cared for person(s) or children's services to the young carer(s) or their family.

Section 24 of the Children (Scotland) Act entitles a carer to request an assessment of their ability to provide care in relation to a disabled child. The local authority must take that assessment into account when deciding what services to provide for the disabled child. Scottish Office guidance said 'this could include a child or young person who is supporting a disabled sibling at home'. Young carers may also qualify for assistance under Section 22, which stipulates local authorities duties towards children in need. Section 94 of the Children (Scotland) Act defines children 'in need'. The definition includes both children adversely affected by the disability of a family member and also children whose health or development is likely to suffer significantly unless services are provided for them. That could apply to those who provide the substantial and regular care addressed above and also other children who provide a lower level or frequency of care.

The local authority has a duty to promote the welfare of 'children in need' and promote their upbringing by their families where this is consistent with the child's welfare. It must do this by assessing the child's needs and by providing a range and level of services appropriate to the child's needs.

The UN Convention on the Rights of the Child also supports the rights of young carers.

Article 2 states that the rights set out in the Convention have to apply to all children without discrimination of any kind. The disability of the child's parents or guardian is specifically included in the list of the kinds of discrimination that the Convention aims to end.

Article 3 states that all actions concerning the child should take full account of his or her best interests. The State must provide adequate care when parents or others responsible cannot do so.

Article 6 indicates that the State must ensure to the maximum extent possible the survival and development of the child.

Article 12 indicates that the child has a right to express his/her views and have them taken into account in all matters affecting him/her.

Article 28 endorses the child's right to education.

Article 31 deals with the child's right to leisure, recreation and cultural activities.

Considerable attention has recently been paid to the need to provide services for disabled parents so that their children are not forced to undertake inappropriate caring tasks or levels of caring. Direct payments are seen as an important means of giving parents control of delivery of services required. The Community Care (Direct Payments) Act 1996 gave local authorities in Scotland the power, but not the duty, to make direct payments to people who have been assessed as needing community care services. Witcher et al (2000) noted that uptake of direct payments in Scotland had been relatively slow; with only 120 people in Scotland receiving such payments in 1999. More recent research by Scottish Health Feedback (published in February 2002) has shown that the number of recipients had increased to 210. The Regulation of Care (Scotland) Act 2001, extends the scope of direct payments to include children. Since December 2001 local authorities have been able to make direct payments to disabled parents to enable them to purchase services their children need. It will be important to monitor the number of disabled people who use direct payments to assist them in parenting and to assess the impact that this has on their children.

A key document shaping approaches to young carers in the UK is the National Strategy for Carers (Department of Health, 1999). This document places provision for young carers within the wider Government agenda of tackling social exclusion. The difficulty of identifying young carers as a discrete group is acknowledged:

There may be only a narrow dividing line between 'helping round the house', which many children do, and providing personal care for a relative. (Department of Health, 1999)

It is also recognised that the relationship of the young carer to the cared for person may vary. The family member may be:

- A parent with a physical illness, disability, mental health problem or dependency on alcohol or drugs;
- An elderly grandparent who is frail or who has a health problem or disability;
- A brother or sister with a health problem or disability.

Children in single parent families, those from minority ethnic backgrounds or from a family where a parent has a mental health problem are recognised as particularly vulnerable. The effects of being a young carer are regarded as generally negative. These include:

- Problems at school with completing homework and in getting qualifications;
- Isolation from other children of the same age and from other family members;
- Lack of time for play, sports or leisure facilities;
- Conflict between the person they are helping and their own needs, leading to feelings of guilt and resentment;
- Feeling that there is nobody there for them, that professionals do not listen to them and are working only with the adult;
- Lack of recognition, praise or respect for their contribution;
- Feeling that they are different from other children and unable to be part of a group;
- Feeling that no one else understands their experience;
- Problems moving into adulthood, especially with finding work, their own home, and establishing relationships.

Inter-agency work in assessing and meeting the needs of young carers is seen as critical. In addition to supporting the work of young carers projects mainly run by the voluntary sector, the Strategy indicates the Government will:

- Aim to ensure that children whose parents or other relatives have specific needs arising out of disability or health conditions, enjoy the same life chances as all other children in their locality. This requires local authorities to identify children with additional family burdens and to provide services that are geared to ensure these children's education and general development do not suffer.
- Do more to make health, education and social services work together on children's services plans, as set out in the White Paper *Modernising Social Services*.
- Continue to emphasise the need for co-operation between adults' and children's services within social services departments. This means, for example, that the community care assessment of a disabled parent must pay attention to that disabled person's role as a parent.

The need to provide coherent services for disabled parents was the theme of a Social Services Inspectorate report (SSI, 2000). Based on inspections in eight local authorities, the report noted that disabled parents were likely to encounter considerable difficulty in finding services to support them in meeting the day to day demands of being a parent. The report recommended that services should reflect the social model of disability, which locates deficit not in the individuals but in the physical, social, political and economic environment in which people live. The SSI noted that services tended to be targeted at either children or adults and resourced through different funding routes. As a result, assessments tended to focus on only one

aspect of the family's circumstances, rather than being holistic and needs led. Amongst other things, the report recommended a radical shift within local authorities towards corporate working, much better management information about the client group, clear budget information and the use of customer satisfaction surveys.

The Scottish Executive has developed its own *Strategy for Carers in Scotland*, published in 1999. The Strategy committed the Executive to addressing the specific needs of young carers by enabling them, for the first time, to have a direct assessment of their needs. They also stated their expectation that all local authorities would pay particular attention to the development of services for young carers. Funds were made available to support young carers through the Family Fund Trust which assists families including a severely disabled child or children living at home, and the Dundee social inclusion partnership, a three year project which aims to identify and support young carers. Other commitments relating to young carers included research to establish the current situation in Scotland, the promotion of support within schools, and the inclusion of young carers in the initial training of teachers. The Scottish Executive promoted more comprehensive arrangements for the regulation of care services through the White Paper 'Aiming for Excellence' (Scottish Executive, 1999a). In January 2000 the Executive set up the independent Scottish Carers' Legislation Working Group to look at what new legislation was needed to support carers better. The Report of the Group (Scottish Executive, 2001) included a brief section on young carers which discussed the legislative anomaly whereby young carers in Scotland were unable to request an independent assessment. Removing this anomaly was one of the Scottish Executive's main commitments in bringing forward the Community Care and Health (Scotland) Act.

The resulting report a brief section on young carers, which discussed the legislative anomaly whereby young carers in Scotland were unable to request an independent assessment. Removing this anomaly was one of the Scottish Executive's main commitments in bringing forward the Community Care and Health (Scotland) Act.

The design of the present study

Much of the published literature has concentrated on the experiences and needs of young carers, as well as advocacy of service and policy responses. Hence quite a lot of the writing is about what *ought to be in place* rather than *actual services*. Most publications have dealt only partly or incidentally with the specific topics for this review. As a result it was necessary to extend the present study somewhat beyond a conventional literature search.

Firstly, it was necessary to abstract from the research and practice literature those aspects which refer to identification and non-identification processes by service agencies, and service approaches and evaluations. In addition it was vital to analyse unpublished material, particularly in relation to the situation in Scotland. This gave access to information that was in some respects more up-to-date and more service specific. Also it extended knowledge about services in the Scottish legal and policy context, which were not widely represented in the formal literature. Contact was made with relevant agencies across Scotland with a dual purpose: to request copies of documents related to young carers and to pose a number of questions about the

agency and its services. Finally we thought it desirable and feasible to undertake a limited exercise in tapping the knowledge of a small number of ‘experts’.

Thus the review has three main elements, which were undertaken concurrently. The first is a review of published work. The applicants already had a stock of British and some North American literature, but in addition carried out a bibliographic search using BIDS and EMBASE. In view of the time-scale, the search was largely confined to English language sources in the last 5 years. Besides using a conventional computer search, the team asked their contacts in other countries about key work they were aware of.

Secondly, the team obtained and reviewed descriptions of services, evaluation reports and other unpublished documents. This part of the review was limited to Scotland, plus any readily available document on important developments elsewhere in the UK. In order to obtain this information, a letter explaining the purpose of the study and a short questionnaire were sent to at least two named individuals in each of the thirty-two local authorities, and fifteen health boards, as well as a number of voluntary organisations. The respondents were asked to provide a copy of any relevant documents. Recipients of these letters were asked to pass a copy of the questionnaire to any organisations working with young carers including groups and young carers projects in their area. Fifty-eight completed questionnaires were received in addition to a considerable number of leaflets, assessment forms, copies of proposals, and reports. Responses were received from most areas, from the Borders in the South to Orkney and Shetland in the North. We are very grateful to all the individuals who sent in responses, which often involved consultation with colleagues as well as the collection of several documents. In order to ensure the confidentiality of respondents, the source of all materials have not been specified, except when they are already in the public domain. In general reports and other ‘dated’ information will be presented in chronological order to give some understanding of the development of work in this field in Scotland.

Thirdly, a small number of ‘experts’ were approached by e-mail and telephone to answer a few questions derived from the objectives of the review. These included academics who have published in this field and representatives of about 8 statutory and voluntary agencies in Scotland and England to provide their overview of assessment and service delivery processes. Table 1.1 provides information on our sample of key informants.

Table 1.1: Key informant interviews conducted as part of the review

Voluntary organisations providing services/projects for young carers	3
Voluntary organisations focusing on disability issues	2
Dundee thematic social inclusion partnership	1
Representative of health board	1
Scottish Executive representatives	2
Academics	2

An interview schedule was prepared which focused on the nature of the organisation, its definition of young carers, how young carers are identified and assessed, the nature of services for young carers and how these might be improved.

Conclusion

In this introductory chapter, the legislation and policy underpinning current approaches to service provision for young carers have been explored. We have also explained the methods employed in this review of the literature of the definition and identification of young carers, the means of assessing their needs and the approach to service provision. In the following chapters, information has been grouped as follows:

- definitions and categories of young carers
- identification processes and inhibiting factors
- needs assessment
- services
- evaluation

Each chapter begins with the review of literature (usually the largest element), then presents separately the data received via questionnaires and key informant interviews.

CHAPTER 2: DEFINITIONS AND CATEGORIES

Introduction

In this chapter we consider definitions of young carers in official policy documents and contrast these with a range of operational definitions. Information is drawn from the research literature with regard to numbers of young carers, as well as their characteristics and types. Key conceptual differences between commentators writing from a children's rights and those adopting a disability rights perspective are considered. Understandings of young carers emerging from the agency survey and the key informant interviews are also considered.

OFFICIAL DEFINITIONS

A full account of legislation relating to young carers is provided in Chapter 1. Here, we summarise and comment on some key features. The Carers (Recognition and Services) Act 1995 defines young carers as 'those who provide or intend to provide a substantial amount of care on a regular basis'. However, the Act does not define 'regular' or 'substantial', leaving this to the discretion of local authorities. Dearden and Becker (1998) argue that definitions of young carers should be broad and inclusive to ensure that terms such as 'regular' and 'substantial' are not used to exclude vulnerable children from receiving an assessment of their needs. The prime consideration, they maintain, should be the probable impact of leaving children to care unassisted.

Section 17 of The Children Act 1989 does not specifically refer to young carers but rather it relates to children deemed to be 'in need'. In so far as young carers' health and development may be at risk as a result of the caring responsibilities they undertake, young carers could be considered as being 'in need' and therefore may benefit from this legislation. As noted in Chapter 1, the Children (Scotland) Act 1995, unlike its English counterpart, identifies children adversely affected by the disability of a family member as children in need as well as those whose health and development may be at risk as a result of their caring responsibilities.

Legal duties in relation to young carers are established through children's and carers' legislation. Jenkins and Wingate (1994) emphasised that young carers require assistance both as children in need and as young carers and should be viewed as both in any definition of young carers.

The most recent policy guidance from the Department of Health recognised the difficulties of establishing a firm legal definition of young carers. The report noted:

There may be only a narrow dividing line between 'helping round the house' which many children do, and providing personal care for a relative. But in the worst cases young people can be harmed by the responsibilities and expectations placed upon them (DoH 1999, p.73).

OPERATIONAL DEFINITIONS

Whilst it is recognised in official policy documents that there is no absolute definition of a young carer, so organisations providing services for this group also vary in the definition they adopt. The three examples below are cited in a research report produced by NCH Action for Children (Scotland) (1997).

Anyone under the age of 18, whose life is in some way restricted because of the need to take responsibility for the care of a person who is ill, has a disability, is experiencing mental distress or is affected by substance abuse. (Carers National Association)

A child or young person (under age 18) who is carrying out significant caring tasks and assuming a level of responsibility for another (adult) person, which would usually be taken by an adult. (Department of Health)

Any child or young person of school age (5-18) whose life is restricted through providing direct or indirect care for a sick, disabled or other family member. (The Kirklees Project: Blyth et al, 1995:13)

Dearden and Becker (1997) describe young carers as:

Children or young people whose lives are restricted because they provide care for sick or disabled family members. They usually care for parents although, less commonly, they may be caring for grandparents, siblings or other family members. The person they care for may be ill, disabled, suffer from mental health problems, problems relating to substance misuse or may have HIV or AIDS. (Dearden, C., Becker, S., 1997, p123)

Dearden and Becker emphasise that *children* who care have a very different legal status from adult carers, and there are considerable dangers in subsuming them within the umbrella group of carers.

....in relation to public and professional judgements and pronouncements, they are often powerless and, despite their considerable responsibilities as carers, are always regarded as subordinate to adults. (Aldridge and Becker, 1993:vii)

Edwards (1997) suggests that the term ‘young carer’ may be misleading, and that the term ‘children affected by illness, disability or substance abuse’ would be more helpful. He pointed out that while these children may have common needs, they will also have specific individual needs, many of which are currently being dealt with by a variety of professionals. Consequently, the resource implications are substantial, although neglecting the problem of young carers may have even greater resource implications in the long term.

Attempts to define young carers encounter a number of tricky questions, for example, what are the criteria for being classed as a ‘young carer’? Does it depend on the

amount of caring, or having prime responsibility for caring? How much weight should be placed on whether young people recognise themselves as carers? Problems in defining who counts as a young carer lead to further problems in identifying which children and young people should have their needs assessed (see Chapters 3 and 4).

Rather than regarding all young carers as identical, some commentators have sought to conceptualise levels of caring. Frank (1995) classified young carers into three groups:

1. *Sole carer* – a child or young person who is the only person in the household with a caring role, as no adult is available
2. *Supportive carer* – a child or young person who assists an able adult who is the main carer
3. *Sibling carer* - a child or young person who helps look after a disabled sibling

In Frank's study, more than half of the young carers were 'supportive' and about a third were 'sole carers'. Other studies have shown that most children who have a caring role with respect to a disabled family member are supportive or sibling carers (Salter 1999; Banks et al 2001). Children in lone parent households where the parent is in need of support are especially likely to take on 'sole' responsibility (DoH 1999).

POPULATION ESTIMATES OF YOUNG CARERS

Whilst there has been much discussion of the characteristics of young carers, only one study, that conducted by the Social Survey Division of the Office for National Statistics (Walker, 1996) has attempted to assess the prevalence of young carers in the population. The aims of the survey were to provide qualitative data on the attitudes and characteristics of young carers based on a general population sample and to investigate whether a standard set of survey questions can successfully identify young carers. The working definition described in the Chief Inspector's Letter of April 1995 was used in the study. A young carer was defined as: A child or young person who is carrying out significant caring tasks and assuming a level of responsibility for another person which would usually be taken by an adult. The term refers to children or young people under 18 years caring for adults (usually their parents) or occasionally siblings. It does not refer to young people under 18 years caring for their own children. Nor does the term refer to those children who accept an age appropriate role in taking an increasing responsibility for household tasks in homes with a disabled, sick or mentally ill parent.

In attempting to estimate the size of the group, the report noted difficulties over definitions. These problems arose as a result of subjective interpretations of what constitutes 'significant caring tasks' and what counts as an 'appropriate role' for a child or young person. In addition, there were practical difficulties in translating the definition into a standard set of survey questions (Walker, 1996).

A general population sample of 12,000 households across Great Britain yielded 29 households which possibly contained one or more young carers based on the application of certain standard criteria. Data from in-depth interviews and further examination of the original data led to an estimated 17 households containing 18 young people who met the DoH's suggested criteria for a young carer (see above).

Estimates based on these findings suggested a total population of between 19,000 and 51,000 young carers. In the light of data from a number of small scale studies, Walker concluded that the number of young carers in GB was likely to be towards the lower rather than the higher end of the range (i.e. 0.2% of the population). The Scottish Household Survey results for 1999, published in Scottish Community Care Statistics 2000, indicated that just over 5000 children in Scotland under the age of 16 were 'providing care to people within their own home' (p. 74). They accounted for 3% of all carers.

A number of small scale studies have attempted to identify the prevalence of young carers in specific areas. A survey conducted by NCH Action for Children (Scotland) (Edwards, 1997) sought to quantify the number of young carers in the South Glasgow District and to identify the needs of these children and young people. The category was defined broadly to include any child living with a disabled sibling or a parent with disabilities, long term illness or addictions. Social work staff in one area, Gorbals, were asked to record how many children and young people within their caseload were potential young carers according to the definition given above. Extrapolating these data to the entire South District, it was estimated that there were 1,024 potential young carers (2.2% of the population).

A study of young carers in Easterhouse (Strathclyde Centre for Disability Research and the Centre for the Child & Society, University of Glasgow, 2000) used a survey of school children conducted by the Scottish Council for Research in Education. Three hundred and ninety three secondary pupils and one hundred and fourteen primary school pupils completed a questionnaire. Respondents were asked if their household included a disabled adult or child. Those who responded positively were asked the following questions:

- What caring tasks do you help with?
- Do you receive any help in caring for your disabled family member?
- How does the time you spend caring for your family member make you feel?
- How do your caring responsibilities affect your time at school?

Three per cent of respondents indicated that they were undertaking a significant amount of caring work (over seven hours a week) for another person in their family, although only a quarter of these said that the person they helped had a disability or addiction.

CHARACTERISTICS OF YOUNG CARERS

In a survey conducted by the Princess Royal Trust for Carers (PRT, 1999) it was found that 43% of participating young carers looked after someone with a physical disability, 26% cared for someone with a learning disability and 13% cared for someone with a mental health problem. A primary carer was defined as 'the only person providing care'. Thirty two per cent of primary carers taking part in the survey cared for someone with a physical disability while 21% cared for someone with a mental health problem. Thirty five per cent of young co-carers (people who share caring responsibilities with others) shared their caring responsibilities with someone less than 18 years old. Fifty per cent of young carers taking part cared for their

mothers (26% of these being primary carers) and 20% cared for their fathers. Forty nine per cent of boys cared for their mother while 18% of girls cared for their father.

The Young Carers Research Group, based at Loughborough University conducted a survey of over 2,300 young people in the UK, the largest study of young carers to date. Those surveyed, who were contacted through young carers groups, were all aged 18 years or less and they provided care and support for ill or disabled family members (Dearden and Becker, 1998). At the time this research was carried out, there were over 100 specialist support projects in the UK.

Dearden and Becker (1998) discovered that the average age of young carers supported by projects was 12. Eight-six per cent were of compulsory school age and over half were between the ages of 11 and 15. Fifty-seven per cent were girls, who were more likely to be involved in all aspects of care, especially domestic tasks and intimate care. Most young carers performed domestic chores, and a fifth were involved in personal, intimate care such as bathing or toileting. The nature of the illness or disability of the care recipient influenced the tasks performed by young carers. Over half (54%) of young carers lived in lone-parent families. Twelve per cent of young carers were caring for more than one person. Fifty eight per cent of all care recipients were mothers. Most care recipients had physical health problems, but over a third of young carers cared for someone with mental health problems. A fifth of all young carers of compulsory school age were missing some school. Twenty eight per cent were either missing some school or had other indicators of difficulties such as receipt of additional educational support or contact with education welfare services. (Dearden and Becker, 1998).

A more recent study by NCH Action for Children (Scotland) together with the West Dunbartonshire Social Inclusion Partnership (undated) had the following aims:

- To quantify the number of children and young people in West Dunbartonshire with a parent with a mental health problem.
- To quantify the number of these children and young people who are taking on a caring responsibilities as a result of their parent's ill health.
- To identify the needs of these children and young people
- To identify the support and information needs of professionals working with children and young people of parents with a mental health problem

The audit was conducted in two stages. Firstly, data were gathered through staff and professionals working with families where there was a parental mental health problem. This was based on the methods used in the earlier NCH Action for Children (Scotland) study by Edwards (1997). At no time were parents or children approached directly.

Respondents were asked to provide statistical information on their caseloads where there were mental health problems, and thereafter detailed information on a sample of those cases where there was parental illness. Respondents were asked to limit the number of cases to five. One hundred and ninety nine forms were sent out requesting this information and 47 were returned, a response of 24%. This level of response was only achieved after two reminders and several agencies did not participate for a variety of reasons.

The information provided by the respondents led to 451 clients with mental health problems being identified. Almost one third of this client group had children, giving a figure of 283 children with a parent with a mental health problem.

- 52% of parents were lone parents
- Almost one third of the children were aged five or less
- Almost two thirds of the children (61%) were aged ten or less

In a second phase of the research, the caring responsibilities of 149 children were examined. It was found that:

- 38% of children were providing some level of care
- Two thirds of young carers (64%) were female
- Children between 6-10 years were most likely to be caring
- Almost one quarter (23%) of parents also had problems with drugs or alcohol
- Almost two thirds (61%) were in receipt of income support
- The numbers receiving some form of benefits rose to 93% if DLA, IB, or Housing Benefit were included.

Over half (51%) of the children/young people experienced behavioural, physical or educational problems.

Meanings and conceptual disputes

A persistent theme throughout this review is the difficulty of establishing common meanings and understandings of what it is to be a young carer. Commentators are not always consistent in their definitions, for example, members of the Loughborough Young Carers Research group conceptualise young carers as performing 'unpaid work' as a labour of love. Their activities correspond with the job remit of certain paid care assistants (Becker, Dearden and Aldridge 2001).

At the same time, Becker et al (2001) assert that the definition of young carers should be as broad as possible and the *amount* of unpaid work undertaken should not be seen as particularly important. Being defined as a young carer acts as a gateway to certain rights, including that of assessment leading on to services. Therefore it should encompass three broadly defined elements:

- the *amount* of caring
- the *significance* of the care to the young person and family
- the *impact* of care work

It is noteworthy that many young people express reluctance to regard themselves as 'young carers', even after exposure to the accompanying ideas at young carers projects (Frank, 1999).

The notion of young carers is also opposed by those writing from a disability studies perspective. Keith and Morris (1996) claim that defining children of disabled or ill parents as young carers '...not only undermines the parent/child relationship, it also

fudges the issue of whether children *should* be performing such personal assistance tasks’.

The young carers literature, Keith and Morris suggest, creates a false dichotomy between the ‘young carer’ and ‘the cared for’, ignoring the disabled parent’s own contribution to caring. In general, the literature fails to distinguish between different types of caring, fails to undertake comparative research with other children on ‘normal’ caring and sharing responsibilities, and blames the parent rather than society and the state for failing to provide caring services (see also Olsen & Parker 1997). Olsen points out that being a young carer is portrayed in wholly negative terms in the literature, for example such children and young people are seen as being socially excluded and as having lost their childhood (Olsen, 1996).

Data from agency survey

The postal questionnaire sent out did not ask specifically for a definition, however, a number of the leaflets and reports received did include this information. In some instances, definitions reflected eligibility criteria for a particular project:

Children and young people whose parents are suffering from mental health problems. This includes those young people who may have caring responsibilities.

[the provider] recognises the needs of children affected by disability and various groups have been set up to support them. The [provider] draws attention to the fact that much of the research has focused on young carers – they believe that the term siblings is less emotive and more appropriate to the age group that they are covering – 6-8 years.

In other cases definitions used by other organisations were adopted:

The Carers National Association has defined young carers as ‘children and young people under the age of 18 who are placed in a position of responsibility for the care of a disabled relative at home’

Some organisations wished to avoid being too prescriptive:

The definition of a young carer should not be restrictive; definitions should be inclusive rather than exclusive. Agencies need to take account of the actual or potential impact of caring on children, particularly where – in the absence of external help children are left unsupported to provide care ... Children and young people whose lives are in some way different because they care for a family member who is ill – they may have a disability, mental health problems, HIV/Aids or be affected by drug/alcohol abuse. As primary carers they spend a substantial part of their time in day to day care or are involved in personal and intimate care of another person.

The majority of projects adopted an approach whereby young people may or may not be primary carers, and disability is defined broadly to include mental illness and drug

or alcohol misuse. A number of respondents were involved in services developed specifically for children and young people affected by mental illness and drug or alcohol misuse and drew attention to the particular problems affecting these young people including chaotic lifestyles, stigma, and a real fear that contact with social services might lead to their removal from the family home. One respondent suggested that the work of their project is *'more about mental health promotion, and resilience building than caring – the issue is about the psychological and emotional effects of mental health and understanding that and coming to terms with it.'* It was suggested that this was a very different approach to the 'social care approach' often adopted with young carers.

Key informants' perspectives

Voluntary organisations working for young carers, sometimes as part of their remit of promoting the interests of carers more generally, supported a traditional view of young carers as children or young people undertaking an unreasonable amount of care and support for a disabled family member or one with a problem of addiction to drugs or alcohol. The Dundee SIP, for example, adopted this definition:

Children and young people under the age of 18 whose lives are restricted because of the need to take responsibility for the care of a person who is ill, has a disability, is experiencing mental distress or is affected by substance abuse/AIDS. (Carers National)

The representative from the Dundee SIP felt that there was no upper or lower age limit in defining who might be counted as a young carer; they might be as young as five or in their early 20s. The amount of work undertaken was seen as less important than its emotional impact. A child who worried a great deal about their parent's illness or addiction may be regarded as a young carer on the grounds of undertaking emotional labour, even if they are not undertaking additional caring tasks. This view was endorsed by a representative from a carers organisation running a project for children of people with mental health problems in a Scottish city;

We can talk about the term young carers if you like, but we tend not to use that term because, when you look at the experiences of the young people that we work with, their traditional caring tasks either don't exist or vary greatly...they are vulnerable for a number of reasons and that is why the project focuses on those vulnerabilities.

It was believed by the Dundee SIP representative that, although girls are more likely to adopt the role of young carers, boys were more likely to be referred for support because the adoption of a caring role was more unusual for them. Whilst not approving of a child undertaking such a high level of caring, young carers organisations felt it was their duty to support them as much as possible.

A Greater Glasgow Health Board representative suggested that the level of social deprivation in particular areas was likely to have an impact on the number of children acting as young carers. In areas of social disadvantage with high levels of alcohol and drugs misuse, a very high proportion of children would be acting as young carers compared with the situation in the leafy suburbs. This view, however, was disputed

by a representative from the Children's Society, who maintained that young carers were to be found in a wide variety of circumstances.

A very different perspective was offered by a representative of the Disabled Parents Network, an organisation offering peer support to disabled parents and campaigning for improvements in services and understanding of the needs and rights of disabled parents. According to this interviewee, the development of the young carers service industry since the 1980s has been 'tragic', because its growth has been in place of services for adults. In her view, there had been no comparable development on the USA or Europe. Whilst young carers as a group appeals to public sensibility, the needs of disabled parents are much less appealing. However, the needs of parents and children are ultimately inter-connected, both requiring support within their families.

A representative from the Joseph Rowntree Foundation (JRF) explained that a Taskforce had been set up to try to find common ground between the disability and the children's rights perspectives. When a social issue led to deep divisions between groups, it was often because it needed to be viewed through a different lens. The JRF Taskforce brought together protagonists of the various interest groups, with a view to achieving such a redefinition. Priority was being given to the disability rights perspective, that if disabled parents were given adequate support, then most were capable of providing good enough parenting without pushing their children into the role of young carers. At the same time, the presence of groups like the Children's Society and the Loughborough Young Carers Research Group served to remind people that in an imperfect world, some children were always likely to be pressurised into adopting caring responsibilities and therefore the need for support for such children should not be overlooked. Children of adults who abused drugs or alcohol, or had mental health problems, were particularly vulnerable and were likely to remain so in the future.

Conclusions

An overwhelming finding from this review of definitions and categories of young carers is that the term is strongly contested. Official definitions of young carers are relative and service providers define young carers in different ways. Attempts at establishing the prevalence of young carers have been stymied by this lack of conceptual clarity. Some commentators urge for the notion of a young carer to be defined as broadly as possible since it acts as a passport to services, whilst others see the term as damaging since it promotes negative perceptions of disabled parents. The latter group advise that the term 'young carer' should not be used at all.

Although susceptible to criticism on the grounds that they do not control for social class or make comparisons with other children and young people, surveys underline the connection between young caring and social exclusion. Such surveys suggest that the phenomenon of young caring is strongly associated with a range of factors linked to poverty and social disadvantage. Many young carers live in families headed by lone parents who are unemployed. Parents of young carers often have problems with alcohol and drugs, and mental health problems are also common. Young carers are

likely to experience a double jeopardy as a result of their caring responsibilities, but also as a result of the educational and social opportunities of which they are deprived.

Whilst most young carers in Scotland appeared to be operating with fairly traditional notions of young carers, it appears that organisations like the Joseph Rowntree Foundation are promoting a more holistic view, whereby services are not targeted specifically at children and young people, but at the whole family and particularly the adults in families where children are performing inappropriate levels of caring work. The thinking here is that if families are given the support to function properly, then the notion of the young carer becomes obsolete.

Finally, the identification of young carers again draws attention to the split between the children's rights and the disability rights perspectives. Whilst the former insists that more effort must go into identifying young carers, that latter suggests that energy should be focused on identifying disabled parents and assessing their needs.

CHAPTER 3: IDENTIFICATION PROCESSES AND INHIBITING FACTORS

Introduction

As we noted in Chapter 2, difficulties in conceptualising young carers, led to considerable confusion as to how they should be identified. In the following sections, we summarise information gathered from the literature review, the survey of Young Carers Projects and from key informant interviews.

Collective identification

The SSI Report of 1996 states that young carers should be identified in both Children's Services Plans and Community Care Plans, which should be cross-referenced. Usually information held within different local authority departments and health services are not in a form which allows for collation of statistics about either young carers or the broader category of children living with a disabled family member (SSI 1996; Banks et al 2001).

IDENTIFYING INDIVIDUAL 'YOUNG CARERS'

Much of the literature considers evidence from research and practice about the kinds of children who may be regarded as young carers, but does not refer specifically to how agencies and projects identify 'young carers'. Several reports do give criteria for admission, e.g. indicating inclusion of children with parents who have mental health problems as well as disabilities.

There have been *three main contexts* for identifying 'young carers'. The first occurs when statutory agencies seek to locate young carers in order to carry out an assessment and/or provide a service. The second has involved young carers projects seeking clientele. The third has entailed researchers investigating young carers' experiences. There have been overlaps, as when research was carried out with a view to setting up a Project (Frank 1995). It has been suggested that some authorities and schemes have been reluctant to seek too widely for young carers out of concern that services would be not be able to cope with the resulting demand for help (SSI 1996).

Usually researchers and projects have located young carers by asking a range of professionals in touch with adults who have a disability or health problem (Frank 1995). Approaching young carers through universal services like schools and health centres risks breaching privacy and confidentiality, so has sometimes been avoided or not successfully accomplished (SSI 1996, Frank 1999). However, the Princess Royal Trust (1999) was able to locate young carers through schools in its study of bullying.

Young carers may have contact with a wide variety of professionals and agencies (SSI 1996). It seems that most children who attend Projects are referred by social work and to a smaller degree health services, with very few being referred by teachers, school nurses or education welfare services (SSI 1996; Dearden and Becker 1998). In a survey of young carers projects in 1997, half the young people and their families were receiving social work support and the leading source of referral was social work services (Dearden and Becker 1998). In contrast, the SSI study found that families had

more contact with health services than social services. In any case, contact with health and social work services is often indirect or peripheral, and does not lead on to assessment or services with respect to the child (Tucker and Liddiard 1998; Sha and Hatton 1999).

Inhibiting factors

Inhibiting factors may primarily reside in the child, the parents or external agencies, although most have an interactive element, as when a child expects or fears certain responses from professionals.

Some factors identified by various studies apply to *both child and parents* (SSI 1996; Aldridge and Becker 1997; Frank 1999; Dearden and Becker 2001). These include various kinds of emotional resistance:

- a wish for privacy
- feelings of shame or stigma
- fear of community reaction
- concern about intrusive professional intervention (family separation, court action, supervision, care orders)

In other cases, it is reported that families might welcome help, but:

- they lack information about services
- they are unaware of their entitlements

The National Strategy (DH 1999) asserts (without citing evidence) that ‘young carers’ from minority ethnic backgrounds and their families are more than usually likely to be suspicious of social services and fear the children will be taken away.

Other factors apply more specifically to *children* (Aldridge and Becker 1997; Frank 1999; Dearden and Becker 2001):

- not liking to be identified as ‘different’ in any way
- not having an identity as a carer
- a sense of family responsibility
- apprehension about strangers taking over caring roles
- pride in the caring role

Frank (1999) noted that, in her sample of 92 children mainly identified through formal services, ‘none of the children recognised themselves as carers’, nor did they like the term, though they could not suggest a better alternative.

Professional ignorance about young carers is linked by Dearden and Becker (2001) to ignorance of legal duties among local authority children’s services and a tendency to overlook children by adult services. Ignorance with respect to young carers may take three forms:

- not recognising that ‘young caring’ exists or is a significant issue
- assuming that the extended family plays a larger role than is actually the case¹
- not realising that particular individuals are young carers

Young carers themselves have reported that they and other children in the family are often largely ignored by social workers and nurses in touch with their parents (Tucker and Liddiard 1998 ‘Young Carers’ in Brechin et al; Shah and Hatton 1999).

Even when workers are aware of the issue, they may lack necessary knowledge and skills. The SSI (1996) observed that staff in adult services might be unfamiliar with children’s needs and communication with children, while children’s services staff do not know about matters related to disability and community care. The SSI also noted that managers might have a commitment to and understanding of young carers, but not front-line staff. The reverse may also occur.

Workers may underestimate children’s competence and misconstrue their vulnerability. This is particularly evident when they ‘protect’ children from ‘difficult’ knowledge by withholding information about their parents’ condition or prospects, when the children in fact have a reasonable awareness but also anxieties that are left unalleviated. Equally, professionals may deprive themselves of important insights about the parents’ situation, which the children may be able to give (Shah and Hatton 1999).

A related matter concerns *professional boundaries*, with some professionals like certain teachers and GPs believing that identifying or assisting young carers is not part of their role (Frank 1999).

A clear implication is the need to include attention to ‘young caring’ in initial and continuing education and training. Croydon established a training post dedicated to young carer issues (SSI 1996).

AWARENESS RAISING

The National Care Strategy (DoH 1999) assumes that many professionals and others are insufficiently aware of young carers and their needs, so they require awareness training. The Strategy refers to GPs, primary health care teams, social workers and teachers. Likewise Dearden and Becker (2001) suggests that the one of the main reasons why young carers are not assessed and do not receive a service from local authorities is the ‘lack of awareness among social services staff about young carers’ needs and rights’ (p. 227).

Often young carers projects start out by making professionals aware of who young carers are and what their needs may be (Frank 1995; Crawforth 1998). In Norfolk, school workers have been recruited using National Lottery money to raise awareness of young carers among teachers and to help them develop support as part of their pastoral care role (DoH 1999).

¹ Several studies showed that relatives outside the household usually played a minor part (e.g. Tucker and Liddiard 1998; Shah and Hatton 1999).

From another perspective, this ‘awareness raising’ can have negative consequences as professionals impose assumptions about young carers (Parker and Olsen 1995, cited disapprovingly in Aldridge and Becker (1997).

Consciousness raising can also apply to young people. Young carer projects provide information to young people in the hope that this will empower them to be more assertive in seeking services (Becker et al 1998).

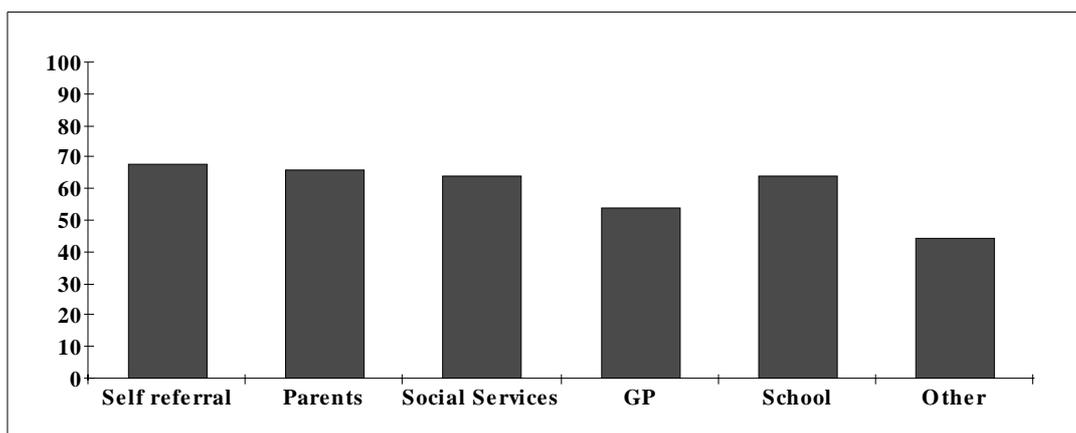
Identification processes and inhibiting factors

Responses to two main questions included in the postal questionnaire are relevant here:

- How are young carers referred to your organisation?
- Are there any factors that might deter young carers from being identified by, or contacting your organisation?

Respondents were asked to indicate whether young carers made referrals to their service directly, and if referrals were received from parents, social services, GPs, and schools. If referrals were received through some other channel they were asked to explain. Eight respondents indicated that they did not provide services directly. Of the remaining 50 respondents, 34 (68%) received self-referrals, 33 (66%) received referrals from parents, 32 (64%) from social services, 27 (54%) from GPs, 32 (64%) from schools, and 22 (44%) from other sources including agencies in contact with the family, health visitors, mental health teams and psychological services, children’s reporter, police, and other voluntary organisations.

Figure 1: Source of referrals to Young Carers Projects (percent)



It can be seen from figure 1 above that approximately two-thirds of respondents received self-referrals, and referrals from parents, social work, and schools. This was followed by GPs and other sources. However, we did not ask respondents what proportion of referrals came from each source, and because some of the projects are small, only a handful could realistically be attributed to each. One project was in the process of appointing a GP support worker who will hopefully raise awareness

amongst GPs and other health professionals. Another respondent reported that identification of young carers may be hampered by:

The tendency of many agencies to focus solely on the needs of their patient/client and not to consider the needs of children/young people within families. Many people have told us that they deliberately visit (adult) clients during the school day so that they can speak to their client uninterrupted.

Other factors that might deter young carers from being identified by, or contacting organisations included; young people who do not identify themselves as young carers (n=16), fear of overzealous social work intervention (n=15), lack of awareness (n=12), the particular problems attached to mental illness and drug and alcohol misuse (n=12), not wanting to be different and the problems of confidentiality in small places (n=9), inappropriate services available (n=5), and transport in rural areas.

Young carers don't always recognise themselves as young carers. Parents are frightened to ask for help for fear of social work intervention. Hidden young carers, e.g. children of parents who use substances e.g. drugs and alcohol, this problem is very much hidden within the family.

A number of respondents sent in referral forms and leaflets designed to encourage young carers to identify themselves as young carers.

One Young Carers Project has a poster which asks:

- *Do you look after someone who has an illness, disability, drug, alcohol or mental health problem?*
- *Are you under 18 years of age?*
- *Do you sometimes miss out on things because of the stuff you have to do at home?*
- *If you answered YES, then you're a young carer.*

Other information aimed at encouraging self-referral avoids the use of the term 'young carer', for example one project uses a picture of a girl in her football gear under the heading:

- *Are You A Supporter?*

The majority of leaflets and posters provide contact details including a named individual, address, telephone number, email, web-sites etc.

We received a number of documents including research reports relating to the identification of young carers in particular localities. Other documents drew attention to work aimed at raising awareness amongst agencies with a child remit, for instance Home School Support, schools, child and family centres, social work departments, associated health agencies and various community organisations, including youth clubs. Young carers packs and other materials including videos have been widely distributed by a number of organisations. The following summaries give some flavour of the type of work that has been carried out.

The two approaches to the identification of young carers were piloted in three different settings (Primary Care, SW and Education) in Fife between 1 Dec 1995 and 31st March 1996 (Price, 1996). In the Primary Care and SW settings presentations which highlighted the issue of young carers were made to health visitors, district nurses and social workers – questionnaires requesting information on young carers were distributed. In the education setting background information on young carers and questionnaires were sent to guidance teachers in high schools and head teachers in primary schools. The study identified 31 young carers, 4 in primary care settings, 15 in social work, and 12 in education. Twenty-seven of the young carers were secondary carers and 3 were primary carers.

Fife Young Carers Action Day: Report 1997 revealed that the Fife Young Carers Development Group (FYCDG) was originally established after a Carers Conference held in Fife in June 1994 with a remit to share information about service provision for young carers. Due to difficulties in identifying young carers the membership and remit of the group were revised. The new remit was to raise awareness of young carers, and thus identify their needs and numbers through the production of an information resource pack for professionals and the production of a magazine for young carers.

- 1500 packs were produced and distributed.
- 78 evaluation forms were returned (9%) response rate.
- 55% of those who returned an evaluation form had used the pack.
- 76% of whom had found it useful

In order to gauge the impact of the awareness raising campaign, delegates at an Action Day were asked about changes in their confidence with respect to young carers:

- 95% reported being aware of young carers and issues surrounding them
- 80% were confident enough to use the Professional Pack
- 45% felt confident enough to identify young carers
- 60% reported being confident that they could support and assist young carers

The West Lothian Young Carers pilot project (1999) conducted a survey in an attempt to estimate the number of young people in caring roles, without great success, and concluded that there could be ‘significant numbers’. Fortunately prevalence figures derived from the Carers National Association and the NCH Action for Children (Scotland), which provided an estimate ranging from 150 to 2,000 (with around 700 having unmet needs) were sufficiently robust to secure funds for a pilot project. In fact staff decided that the pilot project should not be highly publicised in order to avoid creating unrealistic expectations. Those young people (n=10) who were referred were identified through the existing networks of the Youth Strategy Team and Community Education staff. Ages ranged from 11 – 16 approximately.

A second report from West Lothian (Boyle, 2001) also looked at prevalence figures; however, they suggest that getting ‘caught up in the numbers game’ is not a useful activity. In this instance referrals came from a variety of sources:

Schools	34.0%
Social Work	29.0%
Health services	10.5%
Parents	10.5%
Community education	5.3%
Self referrals	5.3%
Voluntary agencies	5.3%

They attributed the high number of referrals from schools to the fact that they have young carers group workers in the schools.

NCH Action For Children (Scotland) & West Dunbartonshire Social Inclusion Partnership carried out an audit which sought to quantify the number of children and young people in West Dunbartonshire with a parent with a mental health problem, and how many were taking on a caring responsibilities as a result of their parent's ill health. The audit was conducted in two stages:

1. Staff and professionals working with families were asked to give statistical information on their caseloads where there was a parental mental health problem, and thereafter detailed information on a sample of those cases. Respondents were asked to limit the number of cases to five. A response of rate of 24% (several of the forms were blank) was achieved after two reminders were sent.
2. A sub-sample of families identified from stage one was selected, respondents who identified each family were interviewed about them. Seventy interviews were carried out with 29 staff – 451 clients with mental health problems were identified - almost one third had children giving 283 children with a parent with a mental health problem. Information is based on 119 parents or families and 231 children showed that just over half (52%) of parents were lone parents, and almost two thirds of the children (61%) were aged ten or less. The relatively low response rate, which several professionals attributed to records that were not accessible, highlights the difficulty in identifying children and young people who may be in need due to parental mental ill health.

A study carried out in Glasgow (SCDR & CC&S, 2000) compared three different ways of deriving an estimate of the number of young carers in a specific area: i) the method used by NCH Action for Children (Scotland) (described above) in a study carried out in the South of the City (Edwards, 1996), ii) The SWIS database, which provided a means of identifying households comprising a person with a disability, *and* a child or children, and iii) a school survey which asked respondents if they helped to care for a member of their family. Estimates derived using the three methods ranged from 2.2% to 6.1% of children/young people aged 16 or under.

Data from key informants' interviews

According to the voluntary organisations and the Dundee SIP, young carers were identified normally as a result of a referral by a professional, usually a social worker providing an adult with services. Child and Family Social Work teams were less aware of young people as carers, but they may realise that young people referred for other issues, such as non-attendance at school, are in fact young carers. Occasionally children self-refer to young carers projects if they are well-publicised.

The process of identification is very difficult because it is essential to ensure that both the child and the parent consent to the referral. Where parents dispute the identification of their child as a young carer, the situation can be very difficult. The Dundee SIP representative said that they worked on the principle that child's needs must come before those of the parents. Some children are in very difficult situation and parents are terrified that social work will remove them from the family home. Where a child is being neglected or abused, then they must be taken out of that situation irrespective of the parents' wishes. A voluntary organisation worker reported that parents with mental health problems were very reluctant to speak about their disability to their children, making it hard for children to make sense of what was happening at home. Factors inhibiting referral were summarised by the Children's Society representative thus:

- children see their caring as part of life, something they just get on with
- children do not want to feel different from peers
- children feel they are managing well
- children are embarrassed and reluctant to speak about their parents' illness or disability and the intimate care they undertake
- children's reluctance to speak about problems when their parents are there
- the child's worry that the parent may have to go into hospital or residential care
- the parents' concern that the child may have to go into care

There was a belief among the voluntary organisations that the number of young carers was under-estimated. The Dundee SIP representative felt that schools and other professionals and voluntary organisations could be much more pro-active in identifying young carers. Teachers, however, could be very insensitive and it was reported that on one occasion a teacher had said to a class: 'Put your hands up all those who are carers'.

To raise awareness among key professionals, the Dundee SIP had produced a video. Work was also underway with teacher education students at Northern College. The SIP hoped that the video would be widely used in the training of a wide range of people working in the caring professions, including doctors, nurses, social workers, teachers, therapists, voluntary organisation workers and community educators. The Dundee SIP representative believed that referral would be improved if more professionals were aware of what a young carer might look like, i.e. tired, dirty, withdrawn, bullied, with low self esteem. The need for the dissemination of information to professionals in many different groups was emphasised by the Greater Glasgow Health Board representative.

Voluntary organisations working for young carers and those with a closer identification with disabled parents believed that there are huge social stigmas attached to caring by children and young people and this keeps the problem hidden. Parents are very unwilling for their children to be seen as young carers, implying that they are 'in need' or 'at risk'. Whereas young carers organisations felt that such resistance had to be overcome in order to meet the needs of young carers, groups speaking for disabled parents felt that such objections were entirely justified. Rather than pathologising disabled parents, the aim should be to provide adequate services to enable them to parent effectively.

A voluntary organisation worker described the multi-layered culture of blame which often inhibited identification, needs assessment and service provision. A child whose parent is ill may stay away from school to look after the parent. A social worker is likely to say to the mother that if she does not get her daughter to school she will be prosecuted and the child taken into care. The child may be told that if she does not attend school, her mother will be sectioned. Pathologising individual players serves nobody's interests. On the other hand, it was pointed out by a Scottish Executive representative that they had to be careful to avoid legitimising non-attendance at school by ignoring the non-attendance of young carers.

Whilst young carers groups pointed to the invisibility of young carers, precisely the same point was made by the group representing disabled parents. All parents were likely to need help with their task at some point. However, disabled parents were particularly unlikely to ask for help because of the negative view cultivated by the young carers movement.

Conclusions

The legislation makes clear that local authorities and health boards should work together to identify young carers with a view to assessing their needs and providing appropriate services. However, given the difficulty of establishing a shared understanding of who should be defined as a young carer, it is perhaps not surprising that so little progress has been made in developing common approaches. In addition, there is uncertainty about whether the purpose of identification is to support young carers in their caring role, or to supply services so that they no longer have to act as young carers. It is evident that identification of young carers may be triggered as a result of seeing a young carer as a child in need, or as a carer. Whilst it may be preferable to use the children's legislation route in identifying young carers, it is evident that this implies defining the child as 'in need' or 'adversely affected by disability'. Both these are stigmatising terms, implying that the disabled parent is failing in their duty to provide care to their child. This negative view of both the child and the adult appears to be the major inhibiting factor in identifying young carers. It appears that most children are identified as a result of social services making contact with adults. Questions therefore arise as to why education and health services are less involved in identifying young carers and what can be done to make them more active partners.

Information from the survey demonstrates not only the difficulty inherent in establishing the number of young carers in Scotland, but also in locating them and determining their needs. Service development and planning are normally founded on demand, which is a function of the number of potential clients, expressed need, and resources. In the case of young carers much of the equation is missing. Neither is there an overall philosophy as to the best way to approach the issue, with some providers spending considerable energy in identifying young carers, while others feel that the 'numbers game' is an inappropriate use of resources. Finally, there is a debate about the usefulness of the term 'young carer', with some of the projects referring to 'supporters', or 'siblings'. Others avoided reference to the purpose of groups altogether, for example the name of one project for young people whose parents have mental health problems reflects its location rather than function.

Finally, the identification of young carers again draws attention to the split between the children's rights and the disability rights perspectives. Whilst the former insists that more effort must go into identifying young carers, the latter suggests that energy should be focused on identifying disabled parents and assessing their needs.

CHAPTER 4: NEEDS ASSESSMENT

This chapter reviews the limited amount of data available about the ways in which young carers needs are assessed. This is complemented by a greater wealth of information and views on the needs of young carers identified in research, suggested frameworks for assessment, and legal and policy requirements

Literature review

Needs identified by researchers and professionals

The literature has much information on the needs of ‘young carers’, mainly identified through research, but little detail is available about the needs assessment processes and procedures of service agencies.

One of the earliest formulations of the types of need was produced by Aldridge and Becker (1993), based on what young people had expressed themselves. The three main needs were for:

- information
- someone to talk to
- practical support

Referring back to their earlier work Dearden and Becker (2000) indicated that the children and young people their team has spoken with had no difficulty in identifying their needs, though it was hard for them to envisage what kinds of services might best respond to those needs. Dearden and Becker went on to state that, with few exceptions, parents in their studies were unable to say what specific needs their children had as carers.

The National Strategy (DH 1999) repeats the conclusion of the SSI 1996 report about what are described as ‘effects’ and ‘disadvantages’ arising from being a young carer:

- problems with completing homework and concentrating at school
- social isolation
- lack of time for recreation
- guilt and resentment as own needs conflict with needs of person needing help
- having no one to listen
- lack of recognition and praise
- feeling different from ‘normal’ children
- feeling nobody else understands
- problems moving into adulthood

Bibby and Becker (2000) observe that children with major physical duties may impair their health. The Strategy document (DH 1999) concludes that the following needs arise for young carers. They need:

1. recognition of their role
2. support with caring (especially to free them to go to school and do homework)

3. information about support and services
4. emotional support and someone to talk to about feelings

A further need described by Aldridge and Becker (1997) is for children to know more about their parents' conditions (e.g. MS), e.g. whether contagious or inherited.

Frank et al (1999) identified the following needs for social and personal support:

- respite care
- support groups
- information about particular illnesses and disabilities
- counselling and advice
- opportunities to shape services

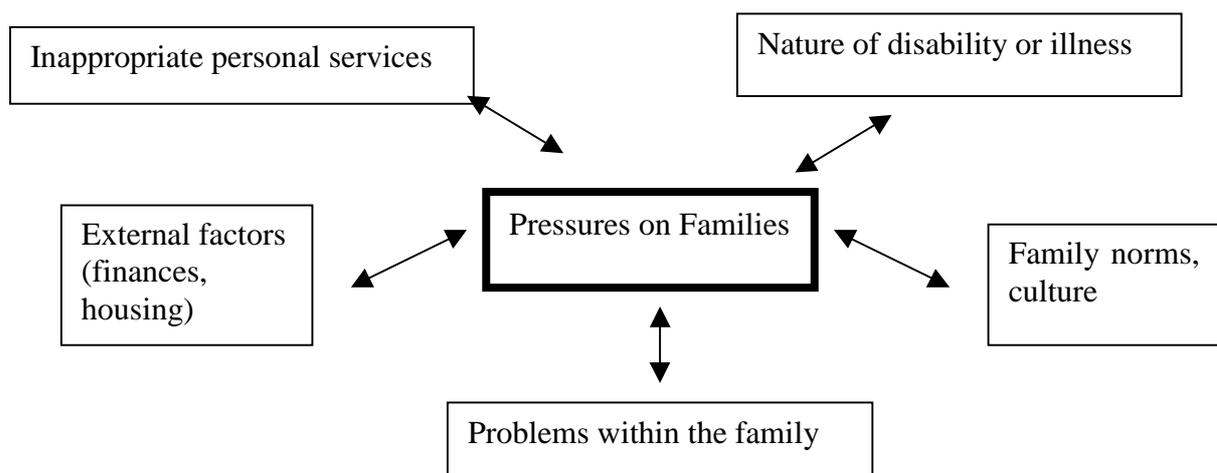
The type of need is related to the parents' situation. For instance, relief from intimate caring is most necessary when parents have a physical impairment, emotional support when a parent has a mental health problem.

The SSI Report (1996) also made reference to parents' needs for domestic help, equipment, counselling and advice.

Several writers emphasise that material circumstances play a major part in generating the needs of both disabled people and young carers. Much of the research on young carers has recognised the effect of poverty, but critics argue that the policy and service implications for financial support have been underplayed in contrast to the emotional and social aspects of caring (Coates 1985; Booth and Booth 1993; Olsen, 1996).

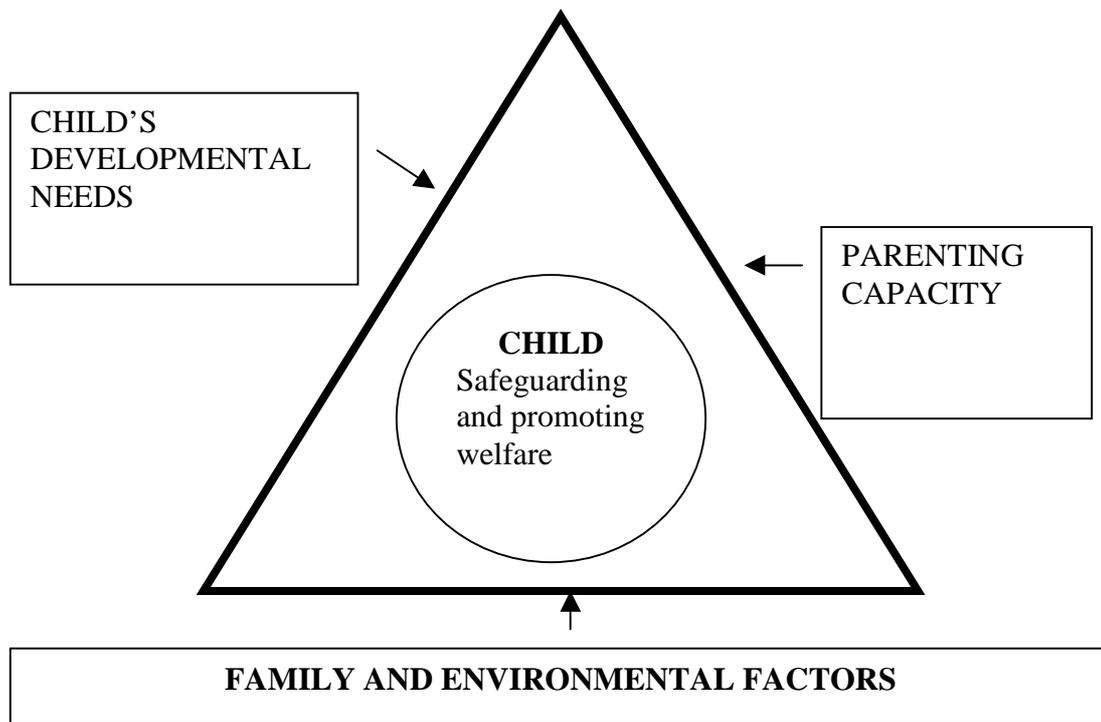
ASSESSMENT FRAMEWORKS

The SSI (1996) outlined a set of factors that should be taken into consideration in assessment:



Parker (1995) distinguished between 'parenting' and 'parenting activity'. The parent should (and normally does) retain responsibility for the child's welfare as the principal carer in the family, but may need help with some of the practical tasks which able-bodied parents undertake.

In England and Wales, agencies and commentators are increasingly applying to young carers and their families the *Framework for the Assessment of Children in Need and their Families*, produced and promoted by the Department of Health (2000). This is based on research findings about parent-child relationships, child development and risk/protective factors. Although the primary emphasis is on within-family circumstances, it adopts an explicit ecological approach and pays attention to external environmental influences and the part played by service agencies, individually and co-operatively. A summary is provided for the framework in the triangle below:



The three domains represented in the sides of the triangle are each divided into several components:

CHILD'S DEVELOPMENTAL NEEDS	PARENTING CAPACITY	FAMILY AND ENVIRONMENTAL FACTORS
<i>Health</i> <i>Education</i> <i>Identity</i> <i>Emotional and behavioural development</i> <i>Family and social relationships</i> <i>Social presentation</i> <i>Self-care skills</i>	<i>Basic Care</i> <i>Ensuring safety</i> <i>Emotional warmth</i> <i>Stimulation</i> <i>Guidance and boundaries</i> <i>Stability</i>	<i>Family history and functioning</i> <i>Wider family</i> <i>Housing</i> <i>Employment</i> <i>Income</i> <i>Family and social integration</i> <i>Community resources</i>

Although developed specifically to cover 'Children in Need' as defined in Section 17 of the Children Act 1989, the Framework does not have to be confined to children classified in that way, whether broadly or narrowly. The Framework report covers a wide range of children and situations, but does include a short section on young carers. This does not specifically apply the Framework triangle, but discusses particular issues relevant to assessing the needs of young carers. It states that 'an assessment of family circumstances is essential' and 'services should be provided to parents to enhance their ability to fulfil their parenting responsibilities' (p. 49). The report notes that the child and adult may have different perceptions about what level of caring responsibility is appropriate, which require resolving by joint work between adult's and children's services. The document reminds local authorities that young carers are entitled to an independent assessment, which must be taken into consideration in the provision of community care services for the parent. When a child's health or development might suffer without the provision of services, then these should be provided 'while not undermining the parent'.

Dearden and Becker (2001) make explicit use of the Framework's 3 main domains. They draw on their own and others' research to describe each as follows:

Domain	Application to young carers
<i>Child's developmental needs</i>	<ol style="list-style-type: none"> 1. Young carers have the same needs as all children 2. Additional needs include: <ul style="list-style-type: none"> • difficulty in attending school, doing homework • isolation • feeling different from peers • lack of time for recreation • specific anxieties related to their parents' condition • embarrassment from giving intimate care
<i>Parenting capacity</i>	<ol style="list-style-type: none"> 1. Parenting capacity is related to the nature of parents' illness or disability. 2. It is important to recognise parents' strengths 3. Parenting may be affected by: <ul style="list-style-type: none"> • limited mobility or strength • reduced or changeable responsiveness owing to mental health problems • poverty and stigma
<i>Family and environmental factors</i>	<ol style="list-style-type: none"> 1. Low income 2. Inadequate housing 3. Lack of community support 4. Prejudice and discrimination

Dearden and Becker (2001) argue in favour of providing services and financial resources for the disabled parents, but also state that many young carers have expressed the need for additional help in their own right, including access to someone to talk over their worries and opportunities to meet with peers in a similar position.

THE LEGAL AND POLICY BASIS OF ASSESSMENT

Potentially, young carers, like other children, may be assessed in a range of contexts for any of several purposes. These include educational, psychological and health assessments. However there are two main types of assessment, which focus on the needs arising from the caring activities of children:

1. General assessments by social work services
2. Specific assessments undertaken by Young Carers Projects with a view to admission

The former have a statutory basis, but this is different in Scotland compared with England and the implications are open to interpretation in certain respects. Part of the uncertainty stems from the fact that the rights and duties were specified at different times in children's and carers' legislation.

Social services departments in England and Wales should use Section 17 of the Children Act 1989 to determine whether a child is 'in need' and therefore entitled to services. The principle criteria are that the child's welfare and development would be

adversely affected if such provisions were not made (DoH 1999). It is also possible that some young carers might be considered to be at risk of significant harm (under section 47). Most commentators think it preferable to regard young carers as children in need rather than at risk, since this offers a route to assessment and services rather than child protection procedures (Family Rights Group 1991; Children's Rights Development Unit 1994; Department of Health 1996a; Dearden and Becker 2001).

The rough equivalent to Section 17 in Scotland is Section 22 of the Children (Scotland) Act, which imposes duties on local authorities with respect to children 'in need'. Section 22 is worded similarly to its predecessor in the 1989 Act, but has an additional subsection or criterion, namely children 'adversely affected' by disability in the family. While the term is negative and potentially stigmatising, it is intended to enable young carers' needs to be assessed and appropriate services provided. Other sections of the Act require that local authorities taking action under Section 22 should give consideration to the child's views and best interests.

The Carers (Recognition and Services) Act 1995 'gives all carers, including those under the age of 18, the opportunity to request an assessment of their needs in certain circumstances' (Crabtree and Warner 1999). This Act, which was implemented from 1st April 1996 is concerned with carers who are either providing or intending to provide substantial amounts of care on a regular basis. A carer aged 16 and over who meets these requirements is entitled, on request, to an assessment when a local authority carries out an assessment (or re-assessment) of the person cared for. The National Strategy (DH 1999) affirmed that young carers can ask for an assessment of their needs in England under the Carers (Recognition and Services) Act 1995, but many are not aware of this.

Crabtree and Warner (1999) suggest that the wording of the Carers (Recognition and Services) Act 1995 is unduly restrictive when applied to children and young people. They argue that 'Definitions of young carers should be broad and inclusive to ensure that terms such as 'regular' and 'substantial' are not used to exclude vulnerable children from receiving an assessment of their needs. The likely impact of leaving children to care unassisted should be the prime consideration.' (p.17). Furthermore, Bibby and Becker (2000) point out that the 1995 Act does not oblige local authorities to provide services if there is no money available.

Until recently, young carers in Scotland have not had the right to request an assessment under the provisions of the Carers (Recognition and Services) Act 1995. This arose because the Age of Legal Capacity (Scotland) Act 1991 provides as a general rule that children under that age do not have the capacity to enter into a transaction having legal effect. In such cases, the parent or guardian would have had to act on behalf of the children (Dearden and Becker 1998). However, the Community Care and Health (Scotland) Act 2002 rectifies the anomaly, so that children can ask for their own assessment. Guidance issued by the Scottish Office in 1996 does state that community care services to adults being cared for by children and young people should ensure that young carers are not expected to carry inappropriate levels of caring responsibilities. It also recognises that denial of proper educational and social opportunities may have harmful consequences on their ability to achieve independent adult life (SWSG Circular No 11/96).

Recent Government policy in many areas has stressed the importance of different agencies working together for the sake of children. For instance, the Scottish White Paper *Modernising Social Services* (2000) and the *Action Plan* (2001) reinforce requirement for health, education and social work services to co-operate on assessment, planning and service provision. The Department of Health in London has recognised that adult's and children's services within social service departments should collaborate. A specific implication is that a disabled parent undergoing a community care assessment must be assessed in the light of their role as a parent (DoH 1999).

ASSESSING YOUNG CARERS

Bibby and Becker (2000) observe that young carers experience a double disadvantage when relating to professionals: as children dealing with adults, and as lay individual dealing with those who have authority and power. It has also been noted that some families are reluctant to take part in an assessment, because they associate social workers with removing children from home (Fischer 1996).

Various issues are meant to be covered in assessments of young carers' needs, but the literature gives few clues about if and how these are dealt with in practice.

The SSI's Practice Guide to the *Carers (Recognition and Services) Act 1995* set out a checklist for assessment, which seeks to combine individual attention to the child with a 'whole family approach' as advocated by Parker (1995).

SSI Checklist

- Listen to the child or young person and respect their views
- Give time and privacy to children who may need this in order to talk about their situation
- Acknowledge that this is the way the family copes with disability or illness
- Acknowledge the parents' strengths
- Beware of undermining parenting capacity
- Consider what is needed to assist the parent in her/his parenting role
- Consider the needs of the child(ren) arising from caring responsibilities
- Consider whether the caring responsibilities are restricting the child's ability to benefit from his/her education
- Consider possible impairment of the child's emotional and social development
- Remember children must be allowed to be children
- Provide information on the full range of relevant support services, young carers' groups and contact points for further advice or information on specific issues

Dearden and Becker (1998) devised a set of guidelines for assessments based in part on their survey about assessment:

- give advance warning
- see the young person separately for at least part of the assessment
- give the young person a choice about the location of the assessment
- explain the purpose and nature of the assessment
- listen carefully to carers
- allow for more than one visit
- encourage the young carer to have an advocate present if desired
- give written feedback
- avoid jargon
- avoid assumptions about gender, age, ethnicity etc
- explain any time-limits if these apply to service provision

Incidence of formal assessments of young carers

Dearden and Becker (1998, 2001) undertook a survey of Project workers asking about the assessments of young people at their Projects. They obtained information on just over 2,000 young people. 11% of these were known to have had an assessment under either the Children or Carers Acts. Younger children were more likely to have been assessed under children's legislation and those in their mid- and late-teens under the Carers Act. Young people caring for an adult with a mental health problem had the highest proportion who had had an assessment. Nine young people were interviewed who had experienced an assessment, but only two referred to it with specific mention of the legislation and the others were vague about the whole process or were unaware of having been assessed. Usually the assessment had led to a service being introduced or increased (e.g. shower installation so the young person no longer needed to assist his mother in the bath). The study by Shah and Hatton (1999) of young carers of minority ethnic backgrounds similarly showed that assessment was uncommon and, when it did occur, poorly understood.

Educational needs

As with most other needs, the literature documents in some detail young carers' educational needs and points to desirable responses to this situation, but does cover the ways in which educational needs are currently identified and assessed by teachers, schools or education authorities. Scottish Office Guidance (SWSG 11/1996) urges social work and education departments to work together when dealing with young carers.

Young carers under the school leaving age should be attending school, unless adequate alternative education is being organised for them. However, studies have shown that between one quarter and nearly half of young carers were missing school (Bibby and Becker, 2000). Two national surveys carried out in 1995 and 1997 found a decrease in the proportion missing school, but this may have been a result of sampling procedures. Not surprisingly, this has been seen to have an adverse effect on educational qualifications (Dearden and Becker 2000). It has been noted that children with a disabled sibling have a heightened risk of school difficulties, though this seems

to be more related to teacher expectations and the reactions of other children than caring responsibilities (Richey and Ysselyde 1983; Dyson 1996).

Assessments of the parents

As noted earlier in the report, some people argue that the most important way of meeting young carers' needs is to ensure that their parents have their needs met and are supported or empowered in their parental role. A disability rights approach entails an assessment of disabled parents' expressed needs for assistance (Keith and Morris 1996; Olsen 1996). A different model requires professionals to make judgements about the ability of parents to discipline children, about behavioural problems in the children, and about the risk of accident and injury to children (Leclere and Kowalewski 1994). This is open to criticism. Booth and Booth have expressed concern about the dangers of professionals stereotyping parents with learning disabilities and argue that parenting competence rather than IQ should be the basis for assessment. They also state that socio-economic factors also have to be taken into account. Similarly, it has been asserted that disabled parents have been judged on different criteria compared with non-disabled parents (George, 1994).

The National Strategy (DH 1999) accepts the importance of assessing the situation of disabled adults as part of a spectrum of measures to assist young carers. It states that community care assessments of a disabled parent must pay attention to that person's role as a parent. Aldridge and Becker (1997) assert that children have a right to take part in family-professional discussions to assess needs and to have information (just like the adults). As with adult carers, it is recognised that assessments involving both parties in the caring relationships require skilful communication and possibly mediation (SWSG 11/1996).

Reviews of needs

Government and others have emphasised that the needs of the disabled person and children should be monitored and reviewed (SSI 1996). This is said to be required particularly when families are vulnerable or changeable (Becker et al 1998).

Findings of the agency survey

The postal questionnaire asked respondents *In what ways are the needs of young carers assessed by your organisation?* Forty-eight respondents answered this question. The majority of comments related to individual assessments, though a few referred to aggregate assessment at the population level.

Individual assessment

Fifteen indicated that a home visit would be carried out initially to establish the level of caring. Typically the purpose of an assessment was to seek to include the young person in a young carers project, so one reason for the home visit was to ensure that parents were happy for their children to be supported by the project. Assessments were usually reviewed from time to time:

Once a referral has been made the organisation writes to the young person to arrange a home visit where an assessment is carried out to determine level and type of caring and how this is impacting on an individual. After 6 months of a young person being with the organisation a review is carried out to see if support needs to be increased/decreased, changed, withdrawn etc.

However, one respondent suggested that professionals often do not carry out assessments because they do not recognise the children's needs. This was related to the tendency to focus on one member of a family as the client rather than taking a more global approach:

Within social work, as services have become more compartmentalised, adult workers do not assess children and young people and children's services workers may not have contact with many of the young people who are affected by a parent or sibling's disability.

Ten respondents reported that their organisations have designed specific assessment tools and others reported that they plan to do so in the future:

Assessment tools were developed by young carers via the support group ... in partnership with social work dept. One assessment tool for young carers, and one for 'older' young carers. The assessment tools are booklets in which the young people are asked to write about themselves – it is divided into sections covering family, who they care for, whether they have anyone to talk to, other people involved with the family, interests etc.

Where assessment tools have been developed they are often used by more than one organisation. Information received from respondents relating to specific projects indicated that the majority have forms which are completed by staff *and* the young people. Details recorded may include some or all of the following:

- Basic demographic information
- Contact details
- Source of referral
- Information about the family, who young person cares for and why they care, i.e. what is wrong with the cared-for person
- Whether the child/young person has any illness/disability themselves
- If the child/young person is a primary or secondary carer
- The type of tasks the young carer does and how often
- How they feel about their caring role
- If the family receives any help from statutory bodies
- What the young carer does in their spare time
- The type of support that would help them.
- Whether the school is aware of the young person's caring role and whether it would be acceptable to the young carers if the project contacted their school.

While most of the information normally consisted of initial details about the child/young person and the family circumstances, some forms have a section for parental input and staff observations.

One respondent drew attention to the fact that assessment can only take place with their parent/s' consent:

Young people are also assessed indirectly (informally) and offered support and services – unfortunately this can only take place with parent's consent.

Another respondent reported that obtaining parental agreement can be difficult:

Only one YC has been formally assessed under the Children (Scotland) Act 1995. This is in spite of the fact that parents/guardians have been made aware of young carers rights as children in need. One assumes that parents/guardians are reluctant to give consent for assessment.

In a more positive tone, the Best Practice Guidelines developed by the Young Carers Partnership in Dundee says that 'With the permission of young carers' parents(s)/guardian the young carer has the right to request an assessment under the Children (Scotland) Act 1995' (Hughes, 2000). Usually agencies have sought permission on an individual one-off basis, but the recent Partnership Report (2001) envisages a mass approach to seeking consent. This document states their intention to write to all the known young carers' parents/guardians and ask if they will give permission for an assessment to take place through social work. The success of this venture is not yet known. The new Community Care and Health (Scotland) Act 2002 gives those young carers who are providing or intending to provide regular or substantial amounts of care the right to an independent assessment of their ability to care.

Aggregate assessments

A number of responses related to population needs assessment rather than individual assessment. This was often carried out as part of the preparation for Community Care or Children's Services Plans. For example in one local authority, staff from the social work department met with young carers groups in order to ask the young people about their needs and how they should be met:

They [the young carers] helped put together this year's action plan for the Joint Community Care Plan 2001/04 and are involved in putting together an assessment form specifically for young carers.

One agency, NCH Action for Children (Scotland), carried out a piece of research in order to quantify the number and characteristics of children and young people with a parent with a mental health problem, and to identify the needs of these children and young people. Information based on 119 parents or families and 231 children revealed that:

- ◆ 52% of parents were lone parents
- ◆ Almost one third of the children were aged five or less
- ◆ Almost two thirds of the children (61%) were aged ten or less

In a second phase of the research, the caring responsibilities of 149 children were examined:

- ◆ 38% of children were providing some level of care
- ◆ Two thirds of young carers (64%) were female
- ◆ Children between 6-10 years were most likely to be caring.
- ◆ Almost one quarter (23%) of parents also had problems with drugs or alcohol
- ◆ Almost two thirds (61%) were in receipt of income support
- ◆ The numbers receiving some form of benefits rose to 93% if DLA, IB, or housing benefit were included.
- ◆ Over half (51%) the children/young people experienced behavioural, physical or educational problems.

From this it may be inferred that many of the families required help with the adults' mental health problems and associated care, finance and matters related to the child's development. It should be noted that on the whole, local authorities appeared to be making few assessments, but did refer children to projects and other services. Projects themselves tended to have informal referral processes and did not normally carry out thorough assessments.

Key informants' data

The Dundee Young Carers SIP had produced two booklets for younger and older children to be used in schools or youth groups for identifying young carers. The booklet posed questions about caring responsibilities, asking them to draw pictures of their family and to describe or draw a picture of who they help and what they do. The booklets were intended to be used with all children in school as a diagnostic tool. However, no guidance on interpreting the data had been developed and the booklets did not appear to have widespread use as a screening tool.

The Greater Glasgow Health Board representative felt that more assessment work should take place in schools, co-ordinated by Joint Assessment Teams (JATs). These teams would include representatives from education, social work, educational psychology and health and would follow children from primary and into secondary school.

Those working for young carers pointed out that whilst the new Community Care and Health (Scotland) Act will enable this group to request their own social work assessment, there was no guarantee that resources would be made available to meet these needs. In addition, it was noted that whilst young carers in England had for some time been able to request their own assessment, this right was little publicised and had been rarely used.

The organisation for disabled parents presented a different perspective on assessing service needs, which they felt should focus on the disabled adult rather than the child

or young person. In particular, direct payments legislation should be used to provide cash payments to individual disabled parents to purchase the services they need to support their family. Flexibility is likely to be particularly important, for example, being able to pay someone to come into the house in the morning to ensure that children leave for school on time.

Conclusions

Plentiful information exists about the needs of young carers as identified and expressed to researchers. These include needs for information, practical support, social activities and counselling. Some writers have suggested that their main need is for their parents to have practical and financial assistance so that the children do not need to assume adult responsibilities. It is not clear to what extent and in which ways community care assessments of adults with children take account of parenting responsibilities.

Similarly, very little publication and collation has occurred of details about the ways in which needs assessments of young carers themselves are carried out, for what purpose or according to which criteria. Nearly always assessments are envisaged with disabled parents in mind and references to care of siblings and other relatives are rare. Sometimes it is assumed that the aim of an assessment is to determine whether a child is eligible to attend a young carers' project: in other words the assessment is service-led, rather than needs-led.

Several holistic frameworks are available for assessing the child, family and social context, but we do not know how common or useful these are in practice. Much attention in the literature has focused on children's rights to receive from local authorities an assessment alongside their parents or independently. It appears that only a small minority of young carers do undergo such formal assessments and, even then, most do not have a good understanding of the reasons and processes.

The agency survey indicated that assessments, when they do occur, normally take place in the child's home. Some agencies have developed dedicated assessment booklets and other tools. For some, a crucial component of the process is seeking to obtain parental agreement for children to attend a Project. It has been suggested that schools or school-based multi-disciplinary teams have a vital role to play in assessing young carers, but again we know little about how much this already happens.

CHAPTER 5: SERVICES

Introduction

This chapter presents information relating to service provision for young carers. Initially attention focuses on the overall approach taken to providing services for young carers and their families. This is followed by a brief overview of the position of the main players, social services, education, health, and the voluntary sector. The support provided by young carers projects is examined together with findings from published literature. Finally the findings from the postal survey are presented giving a flavour of the current situation in Scotland.

Legal entitlement to services and government commitment to provision

Young carers are entitled to support from local and health authorities under legislation contained in the Children Act 1989, the Children (Scotland) Act 1995 and the Carers (Recognition and Services) Act 1995. Since April 1990 the UK Government and Scottish Executive have expanded the support available to all carers, including young carers.

The Carers (Recognition and Services) Act 1995 emphasises the idea of service support for carers and has generally widened the range and reach of support for informal carers. However, the Act has been criticised for not incorporating a commitment to ongoing resources. In many cases services for carers have been withdrawn or cut because of the financial pressures on local authorities, potentially leaving the rights of all carers seriously compromised. Carers National Association 1997, *Still Battling? The Carers Act one year on*, Carers National Association, London, in Michaela Schunk, *A Place For Support: New Policies for Informal Carers In Long-Term Care Programmes*, April/May 2000, in *Benefits*, p.22-5

APPROACHES TO SERVICE PROVISION FOR YOUNG CARERS

Services may be reactive or preventive, although there is often some degree of overlap. As with assessment, 'reactive' service provision may be mainly oriented to young carers or to the family as a whole.

Preventive services

Aldridge and Becker (1997) stress the importance of developing preventive strategies to enable children to lead lives 'unfettered by substantial or primary caring responsibilities' (p.1). They suggested that some caring by children is probably inevitable, since it is 'unrealistic' to expect all the caring needs of certain parents who are chronically ill or disabled to be met by people from outside the home. Hence they see it as more realistic to reduce the caring responsibilities of children.

Disability rights perspective

Keith and Morris arguing from a disability rights perspective highlight the way in which allocation of resources and delivery of services by social services departments creates a need for disabled people to rely on other members of their family, including

children. They quote Gillian Parker from her paper *Where Next For Research on Carers?* (1994). Nuffield Community Care Studies Unit, Leicester University.

“While it seems true that children with disabled parents find themselves carrying a level of responsibility in excess of that of their peers, they do this because their parents are inadequately supported, not necessarily because their parents are disabled.” (quoted on p.95. . Keith, L. , Morris, J., 1996, Easy Targets: A Disability Rights Perspective on the ‘Children as Carers’ Debate, in Morris, J.(Ed.), 1996, Encounters with Strangers: Feminism and Disability).

Financial support for Independent Living

Keith and Morris also support The Independent Living Movement in so far as they point out that by receiving the help they need; disabled people do not necessarily become dependent. They argue that if the person in need has the opportunity to decide for themselves how they receive such help then they will continue to be independent and carry full responsibility for themselves. Although Keith and Morris accept that in certain circumstances the support needs of a caring child should be met, they also claim that if the practical assistance and personal care needs of the parent were met the emotional well-being, and the educational and social opportunities of the child would not be at risk. Keith, L , Morris, J., 1996, *Easy Targets: A Disability Rights Perspective on the ‘Children as Carers’ Debate*, in Morris, J.(Ed.), 1996, *Encounters with Strangers: Feminism and Disability*).

Aldridge and Becker (1997) acknowledge the approach advocated by Parker and Olsen and Keith and Morris, however, they believe that it is simplistic and in the realm of rhetoric. They ask *How long will it be before this ideal scenario is realised?* (p.16). [Ironically major resources have been put into young carers services in a way unimaginable in 1990]. Aldridge and Becker indicate that comprehensive disability support services do not exist and are unlikely to expand significantly in the short run, so that other action is needed. They say the current ‘pressurised and residual welfare system’ will not resolve the problem. They also argue that, even if disabled parents received more practical assistance, there would still be a level of care needs which welfare services are not in a position to meet. They refer for example to night-time care.

Young carers approaches

Becker et al (1998) views the young carers approach as founded on children’s rights to be considered as individuals as well as members of a family. They have rights as children (not to have excessive responsibilities) and as carers (to support). According to Dearden and Becker whether or not families receive external services is a critical factor in determining whether children adopt caring roles in the first place. Thereafter, it continues to be a major factor, influencing the level and nature of the support young carers provide (Dearden, C., Becker, S. 1998 *Young Carers In The United Kingdom (A)*). Of the young carer’s families surveyed in 1997 (*Young Carers in the UK*) only half (50%) had services provided through social work departments; one quarter (25%) of the families had received no external support at all (Dearden, C., Becker, S., 1999, *The Experiences of young carers in the UK: the mental health issues*)

Disability rights proponents see parents needs and rights to autonomy and services as fundamental, with certain young people having additional or separate needs. The young carers movement thinks that the children's protective and participatory rights are crucial, but are also interdependent with their parents' needs. However, Dearden and Becker state that most of those writing about young carers, irrespective of whether they come from a children's rights or a disability rights perspective, agree that support should be family-based and that the needs expressed by all members of a family should be considered in the planning or allocation of service provision to meet those needs. Dearden, C., Becker, S., 2000, *Listening To Children: Meeting The Needs Of Young Carers* in Kemshall, H., Littlechild, R. (Eds.), *User Involvement and Participation in Social Care: Research informing Practise*, London: Jessica Kingsley. The 'whole family' approach argues that offering support either to the young carer or the family member who is ill or disabled is not sufficient, support for the whole family is essential. Bibby, A., Becker, S., 2000, *Young Carers In Their Own Words*.

Family approaches

Over the last few years and partly in response to the debate between the young carers' movement and disability rights perspectives, some Projects have shifted to a more 'family-oriented' approach (Bibby and Becker 2000). Thus, although the majority of Young Carers Projects remain primarily child-centred, there has been an increasing attempt to meet the needs of whole families (Dearden, C., Becker, S., 2000, *Listening To Children: Meeting The Needs Of Young Carers* in Kemshall, H., Littlechild, R. (Eds.), *User Involvement and Participation in Social Care: Research informing Practise*, London: Jessica Kingsley). Providing services to parents has been found to reduce the pressures on children, for example the Cleveland's Sensory Loss Team found that offering interpreters, equipment and peer support to the parents and recruited social workers with non-hearing parents who could offer 'understanding, role-modelling and language skills' helped their children (SSI 1996). Other examples of projects that have adopted a more family based perspective include the St. Helens young carers project which aims to "acknowledge and value diversity in family life." They set up a family support group "based on the principle of self-help to enable families to enjoy life together or with others with similar interests" (P.23 Aldridge + Becker, 1998, *Surge of Support*). A project in Hull arranged meetings for parents, who identified matters they wished to pursue as a group.

Aldridge and Becker (1997) assert that children have a right to take part in family-professional discussions to assess needs, and that young carers projects should co-operate with and compliment support services for ill and disabled people. They should not distract statutory organisations from their duties to arrange or provide services for ill or disabled people or to children in need" p23 Aldridge + Becker, 1998, *Surge of Support*

INTER-AGENCY COLLABORATION: THE MAIN PLAYERS

The Government believes that inter-agency work is important for supporting young carers, and that links between services should be a priority. In the white paper *Modernising Social Services* the UK Government states its commitment to health, education and social services working together to develop children's services plans.

There has also been recognition of the need for adults and children's services to co-operate within social service departments, e.g. a disabled parent undergoing community care assessment must be assessed in the light of their role as a parent.

The Scottish Executive is committed to the development of joint working, including information sharing, systems integration, and the promotion of single shared assessments (see e.g. *Aiming for Excellence, 1999*). This has considerable implications for service providers who may be involved in the identification of, and provision of services for young people who take on a caring role.

The UK Strategy for Carers (1999) reported that inter-agency support projects are proving to be successful in so far as they are encouraging more young carers to identify themselves as carers, reassuring them that support from teachers is available. The document indicated that young carers are now seen to be "confident that they will get support from teachers and referrals to other services as necessary." While it might be suggested that this was a somewhat optimistic assertion, there is little doubt that a range of agencies are now communicating in a way that was unheard of in the 1980s. However, much of this progress has emanated from individual initiatives leading to lack of uniformity between areas.

In part inequities in provision are attributable to access to funding and acceptance of responsibility by a particular organisation. In some areas the provision of services for young carers may be commissioned by social services, whereas in others it may be a joint initiative between health and children's services, or some other combination. In many instances funding is accessed through a variety of means including statutory organisations and charities. This funding is rarely secure and the general lack of resources causes serious problems for the running of projects. Less than half of the projects listed in the handbook believed they would secure further funding after their current budget ran out and "current arrangements came to an end". This insecurity means projects face difficulties when considering taking on new referrals, as raised expectations may not be met (p 23 Aldridge + Becker, 1998, *Surge of Support*). Interagency collaboration can lead to fruitful partnerships between organisations for example the Strategy for Carers highlights the case of Norfolk County Council Social Services which was involved in three inter-agency support projects aimed at benefiting young carers. However, not all collaborations are successful, and trained workers may spend more time applying for money than working with children/young people. Several writers comment on the poor co-ordination that often occurs between adults and children's services within social services and social work departments. They point to the need for protocols and joint working, so young carers are not overlooked (Dearden and Becker 2001).

Social work services

Many of the early services were reactive, seeking to alleviate the difficulties young carers were experiencing by offering support and relief. However, support was primarily targeted at the children and young people, there has been a striking silence about practical caring services to parents.

A study carried out by Aldridge and Becker (1998) revealed that around one tenth of specialist support services for young carers were within social service departments.

Individual project workers, within social service departments, were responsible for the assessment of young carers and their families, indicating an increasing recognition of young carers. Despite this, later research focussing on young carers' transition to adulthood found that about one third of the respondents had no on-going services at all. There were a variety of reasons for this, but refusal or cancellation of services by families was much more common than refusal to provide on the part of social services. Dearden, C., Becker, S. 2000, *Growing Up Caring, Vulnerability and Transition to Adulthood - Young Carer's Experiences*.

In 1996 the SSI listed the kinds of services families wanted and needed. These largely related to assistance for the disabled adult, which *ought* to be available from local authorities and health services:

- ◆ information about services, benefits, illnesses and disability
- ◆ home-based dentistry, physiotherapy, nursing etc
- ◆ domestic help
- ◆ respite
- ◆ adaptations and equipment
- ◆ 24-hour support
- ◆ a key worker
- ◆ counselling

An accompanying list of principles was given, namely that services will be:

- ◆ integrated with informal arrangements
- ◆ co-ordinated
- ◆ culturally appropriate
- ◆ sustainable over time
- ◆ flexible
- ◆ timely, sufficient, consistent and secure
- ◆ available 'without a battle'

Respite care has been found to provide significant benefits for many young carers. However, Francis (1995) pointed out that in order for young carers to qualify for respite care provision they must first be classed as adults. Furthermore, the financial cost of providing respite care for children could be substantial, as such care requires the young person to be accompanied by an adult. Francis, J. 1995, Support for carers, in *Community Care*, 1059, p23-4. Cited in Watson, S. 1999, Meeting the needs of young carers, in *Nursing Standard (journal)*, volume 13(31), 21-27 April 1999, p37-40, RCN Publishing Company.

Schools

The DoH document *Caring about Carers: A National Strategy for Carers* (1999) argues that teachers have a key role in identifying and assisting young carers as a result of their general duty of care. The strategy document also advocates the allocation of dedicated staff (it does not say how this might be paid for or that they must be teachers), who could liaise with the relevant services, linking young carers, the education welfare service, social services and young carer's projects. Similarly the

Scottish Executive's *Carers Strategy* (Scottish Executive, 1999b) encourages initiatives to assist young carers in school.

Several surveys of young carers experiences have revealed school-related problems, such as difficulties in finding time for homework, tiredness and not being able to attend at certain times (Frank 1995; Banks et al 2001). Bullying at school has figured prominently in young carers' concerns (Frank et al 1999; Princess Royal Trust 1999), however, without comparative data on other children, it is hard to know whether young carers are particularly liable to be bullied, since bullying is known to be widespread. However, the Princess Royal Trust found that one fifth of their sample of 240 young people attending Projects said they missed school as a result of bullying and one third thought their teachers did not know they were young carers.

Frank (1995) described how home tutors can directly assist children not attending school regularly, as well as improve school-parent communication, and concluded that key educational support needs are:

- ◆ help from guidance teachers
- ◆ flexible programmes of school work
- ◆ greater awareness of teachers about young carer
- ◆ a link person to co-ordinate provision for young carers
- ◆ good liaison with other services
- ◆ pro-active careers guidance

Health services

On the whole, less attention has been paid to the role of health services than education or social work. As with local authority community care services, Frank (1995) found GPs very unresponsive when invited to identify young carers. GPs have historically been used to seeing and treating just the individual who is disabled or suffering ill health. This process does not lend itself to taking into account the full family context. A simple question asked by the GP of their patient in this situation - *who is helping to care for you?* - might be a trigger to identify the needs of young carers and to enable action to be taken on their behalf. Young carers have expressed the feeling that there is nobody there for them, that professionals do not listen to them and are working only with the adult. Bibby, A., Becker, S., 2000, *Young Carers In Their Own Words*

In an article published by the RCN the role attention was drawn to the potential for nurses in all fields to identify and support young carers. Because they work in people's homes community nurses and health visitors have a front line role in identifying young carers and offering support, information and advice. In the case of hospital admissions, where it may be the first time that a person with a long standing health complaint, and his or her carer, have come into contact with health professionals, hospital nurses are in a primary position to identify young carers and enquire as to their needs. Thus hospital staff also have an important role in helping young people who care for a parent or other relative, and should be in the position to offer appropriate information, advice and support (Watson, S. 1999, Meeting the needs of young carers, in *Nursing Standard* (journal), volume 13(31), 21-27 April 1999, p37-40, RCN Publishing Company).

In a study examining depression and self-esteem in a matched sample of 20 young carers and 20 non-carers it was revealed that 17 out of the 20 young carers had never had any contact with medical professionals and five did not even know the nature or name of the illness that affected their relative. The researchers highlight the point that many young carers were found to be ignorant of their parent's condition and they also accuse professionals of not offering sufficient assistance. Galloway, J., Mayes, G. 1999 Depression and Self-Esteem

MENTAL HEALTH ISSUES

In addition to the high levels of stigma associated with mental health problems, and the way in which this deters young carers and their families from revealing their circumstances and needs, there is another major barrier to the receipt of services facing people in this position. Dearden and Becker (2001) reported that adult mental health services tend to neglect the needs of their patients' children. One of the main problems with measuring the level of support provided by young carers to people with mental health problems is that the nature of support tends to be more emotional than that provided to people with a physical illness or disability. This makes it difficult to quantify the level of support young carers provide to people with mental health problems, so complicating the issues surrounding rights to assessment and the question of appropriate service provision through various organisations. Dearden and Becker highlight the lack of specialist support received by those caring for someone with mental health problems. They reported that even though 30% of young carers support someone with mental health problems only 7% of the total services received was as a result of the participation of community mental health nurses. Dearden, C., Becker, S., 1999, The Experiences of young carers in the UK: the mental health issues.

VOLUNTARY ORGANISATIONS: YOUNG CARERS PROJECTS

The great majority of projects are run by voluntary organisations, though usually with statutory funding (Becker et al 2001). Key providers include the Princess Royal Trust, Barnardo's, NCH Action for Children (Scotland) and Crossroads (Becker et al 1998). From 1992-95 the number of young carers projects increased from 2 to 37 across the UK. By 1998, when the National Handbook of Young Carers was published, the number of young carers projects identified in the handbook was 110. However, Dearden and Becker drew attention to the fact that many areas around the UK were still lacking the specialist support of young carers projects at that time (1998, Unknown Quantity).

In 1999 the Government put the onus onto local authorities to "sustain and enhance the number of young carers' projects" (p78 Caring about Carers: A National Strategy for Carers, 1999). The Carers Strategy of the Scottish Executive urges local authorities to develop better support services for young carers. Since the late 1990s there has been an exponential increase in the number of projects. However, it should be borne in mind that many are reliant on short-term funding and face financial insecurity (Becker et al 1998; Frank et al, 1999), and that for many young carers and their families this may be the only support that they receive. In their study of 2,300 young carers Dearden and Becker found that a quarter of young carers and their families received no support services other than help from a young carers project.

(Becker et al 2001), although not all those who attend Projects will have significant caring roles (Frank 1999; Banks et al 2001).

Young carers projects may provide some or all of the following:

- ◆ **Support groups:** Young carers projects normally run groups, where young people take part in recreational activities, have discussions and receive information (e.g. Frank 1995; Becker et al 2001). The leisure activities provided fun time-out for the children and relief for the adults. Groups for younger children are typically more activity-based, while young people in their teens are more likely also to have discussions of common issues (Taylor 1999). Projects also often give the young people access to an adult for individual advice and counselling.
- ◆ **Information:** The provision of information is an important role for young carers groups, particularly age-specific information relating to particular conditions. Aldridge and Becker (1997) describe the value to children (and parents) of explanatory leaflets spelling out the implications of conditions such as Huntingdon's and Parkinson's, which have been developed by the respective societies.
- ◆ **Befriending:** In addition to offering support groups, some provide an individual befriending service. The Children's Society set up a Befriending Scheme for young carers in the Winchester area. The Befriender's role was to 'listen to the young person in a confidential setting and to actively encourage them to pursue an interest or activity of their choice outside the home' (Taylor 1999, p. 4). Hence it had both counselling and recreational functions, with an emphasis on maximising the young person's participation in making choices and in social activities. The need for the service was suggested by young people reporting a sense of isolation or having issues they could not talk to their parents about. However, the befrienders did not work exclusively with children but also helped and listened to parents.
- ◆ **Home visits:** Some project staff make home visits, which will usually include the parent(s), to assess support needs (DH 1999).
- ◆ **Advocacy:** Many projects also take on advocacy and awareness raising functions (Becker et al 2001). Most young carers are unaware of their rights and advocating on their behalf to secure these rights under current legislation is an important aspect of the work carried out by many young carers projects. (especially under the Children Act 1989 and the Carers (Recognition and Services) Act 1995).

Most projects are *generic*, in the sense of serving all children with some kind of caring or support role towards a family member. However, some are *specialist*, for instance concentrating on certain groups of young carers, such as black or Asian young carers or those whose parents have mental health problems or addictions (Becker et al 1998; Aldridge and Becker, 1998, Surge of Support).

Some young carers projects endeavour to influence local policy and practice, and use awareness-raising strategies in an attempt to ensure that the needs and rights of young

carers are recognised and met by statutory and voluntary agencies (Aldridge + Becker, 1998, Surge of Support).

Tailoring services to fit with young carers needs and wishes

Most people agree that whatever the nature of the service, children should have their views taken into consideration, as emphasised by Article 12 of the UN Convention on the Rights of the Child and various sections of the Children (Scotland) Act 1995. Not only is this a matter of children's rights, but also of ensuring that services are responsive to felt needs. Dearden and Becker (2001) claim that:

Young carers will be empowered if their competencies and experiences are acknowledged and their views sought.

It is important to accept the strengths and weaknesses of diverse family types. Children themselves must be directly involved in evolving strategies otherwise much time and effort can be wasted in well-intentioned but misguided attempts by adults to produce solutions that children may find inappropriate. Beazley, S., Moor, M. Family Lives Of Hearing Children With Deaf Parents. Carers National Association has worked in conjunction with children and young people who care in developing informed systems and strategies of support for them. Throughout the 1990's young people have been actively represented on project steering groups and committees, raising awareness of their needs and so directing service providers to meet those needs. The needs and experiences of young carers, as expressed by themselves, (Dearden and Becker 1998, Young Carers in the UK) have been incorporated into the National Carers Strategy through some of the policy recommendations put forward by the Young Carers Research Group (Dearden and Becker, 2000).

SERVICES FOR YOUNG CARERS IN SCOTLAND

The postal survey sent to organisations in Scotland asked respondents to provide details of their service provision, and if they had contact with other organisations that provide services for young carers and their families. Questionnaires were sent to at least one person in each of all 32 Scottish local authorities and 15 Health Boards, plus 17 voluntary agencies. The contact person was asked to forward a copy of the questionnaire to relevant officers and projects, which many did. The number of returned questionnaires was fifty-eight. Information in this section is derived from individual responses and details provided in reports and documents relating to specific projects. It should be borne in mind that, although access to resources and size of project do not necessarily equate with 'good practice' or the emergence of innovative ideas, they may be associated with the quality and quantity of promotional materials. Thus we may have received more detailed and eye-catching information from some projects than others.

Interagency collaboration

Respondents were asked how much contact do you have with other organisations that provide services for young carers and their families?

Fifty-one respondents answered this question, all of whom reported some form of contact with other organisations including representatives from local authorities, social work, health, other carers projects, police, etc. The level and type of interaction appeared to depend on the size and geographical location of projects for example:

There are no specific services for young carers in the region other than our project. However we work with other organisations that may be able to support young carers e.g. local family projects, toy libraries, play therapists etc.

Respondents drew attention to the benefits to be derived from communication with other organisations:

Our staff meet with workers from other young carers projects on a national basis at the Carers National Forum, which meets once per month. This forum offers the opportunity to meet other projects, both local and national. This is useful because there are differences across the country between services that are offered within a semi-rural area and a city project. There are also differences between projects based in Adult Carers projects and those like our own which is part of the work of a child focused agency.

Services

A small number of projects provided support specifically for siblings, who may or may not be young carers, and children/young people who have a parent or parents with mental health problems. However, most projects were generic and catered for *all* young carers irrespective of their relationship to the ill or disabled family member, or the nature of their illness/disability. The majority of projects adopted a similar approach providing some or all of the following services, depending on human and financial resources, and how long the project has been in existence:

- ◆ Group activities often in age-specific groups e.g. 8-12 year olds and 13+
- ◆ Individual support/one-to-one counselling
- ◆ Befriending
- ◆ Provision of information e.g. illness, disability, dealing with stress, applying for jobs, finance etc.
- ◆ Regular magazine (which may or may not be written/developed by young carers themselves)
- ◆ Advocacy
- ◆ Homework clubs
- ◆ Social outings
- ◆ Outdoor activities
- ◆ Residential trips
- ◆ Training e.g. personal safety; confidence building, acceptance of difference
- ◆ Particular support for young carers from minority ethnic cultures
- ◆ Some projects extend support to include parents

Transport is usually provided, and groups may run weekly, fortnightly, or monthly. Several projects work in partnership with social work and schools in order to promote awareness and identify young carers. Members of one young carers group have been provided with support at their schools. This was facilitated by an established relationship between the Youth Strategy workers and the schools. Initiatives to date have included study groups, one-to-one support on specific issues, and early intervention on poor attendance.

Most of the projects provided support on an open-ended basis, which has implications in terms of capacity as one respondent explained:

Children tend not to leave... one of the things that we didn't anticipate at the beginning is that children live in families with other children ... and we have a family of four on the waiting list ... you don't get four places in the groups all at the one time ...just now there are nine people on the waiting list

One project reported that they provided support to young carers on a fixed-term basis of approximately nine months. In addition to weekly groups the young people, approximately ten per group, are encouraged to become involved in local activity based clubs or groups. Before joining the club many of the young people had no active involvement in any community groups. A high proportion of the children/young people lived in single parent families and it would be hoped that once these activities had become an established part of their lives they would continue to attend.

The importance of involving young people in the development of their own services was mentioned by a number of respondents:

We consult with young carers on service provision and have held two evenings where they have met with NHS Board and Council to tell us what they think of services and service development.

The young people set the agenda and manage their own budget and agree a programme which addresses their needs...

It can be seen that the majority of services take a similar approach, i.e. providing 'time-out' and leisure activities for young people. Benefits for parents were rarely cited although a small number mentioned supporting the whole family:

[The project] plays a vital role in advocating on behalf of families for appropriate support and access to services.

Barriers to the provision of appropriate services for young carers

The postal survey asked respondents if there were any specific barriers to providing the type and level of service for young carers and/or their families that you would like to provide?

Forty-nine respondents answered this question. Thirty-six mentioned difficulties caused by lack of resources:

Support for young carers is not included in our core funding. Fundraising activities organised by the carers centre has been our only source of funding to date. This significantly impacts on the type and level of service we can provide ... From June 1999 until June 2001 [the] centre provided time-out activities for an average of 15 young carers on a fortnightly basis ... sessions suspended in June of this year due to lack of resources.

Nine respondents mentioned difficulties associated with the rural nature of the areas in which they operate. Transport was cited as an issue by another nine respondents – even in urban areas transport costs can be high. Other issues mentioned included lack of awareness amongst professionals who do not refer young people, the reluctance of young carers to be identified, parental fear that asking for assistance indicates that they are not coping, and the inability to have young carers assessed in their own right:

The main barrier is the age of legal capacity act whereby young carers under 16 years require parental consent in order to be assessed under the Children (Scotland) Act 1995, as children in need.

However, since the questionnaires were returned the Community Care and Health Bill, passed by the Scottish Parliament on 6th February 2002, gave carers under the age of 16 the right to request an assessment. The impact of this major step will be watched with interest.

Optimum provision

The last question in the questionnaire asked respondents what they would do to address the problems faced by young carers living in their area if resources were available. Fifty-two respondents answered this question. Interestingly nothing particularly novel was suggested – responses revealed that respondents believed the approach taken and the range of services currently being provided are appropriate, but that not *all* projects are able to provide the diversity and level of support that they would like. The difficulties associated with short-term funding were highlighted, both in terms of retaining skilled staff and maintaining services for young people in the longer term. Sixteen respondents indicated that they would employ more support and development workers, six drew attention to supporting young people within schools by providing link staff and supporting young people with homework etc.

Implementation of the recommendation included in the National and Scottish Strategy for Carers including the identification of liaison workers for young carers in schools to promote their needs and rights.

Ten respondents would put more resources into raising awareness, seven would provide transport for young people to go on trips etc. Other suggestions included looking at ways to help young carers in rural areas, and the provision of more computers for communication, training, and the provision of information. Attention was drawn to the importance of providing support for the *whole* family, and the

disabled person in particular, in order to reduce the need for children and young people to provide a caring role:

Best way of supporting young carers is by promoting adequate support in their family.

Conclusions

This chapter has presented information relating to service provision for young carers, including a brief description of the major players. This was followed by the findings from the postal survey which revealed that, in Scotland, the majority of projects take a child-centred approach and provide a range of services designed to give young people an opportunity to have fun with others in a similar situation. Information relating to specific conditions and one-to-one counselling is usually available. The majority of respondents from young carers projects reported that they interacted with other young carers projects either locally or through the Young Carers Network, sometimes sharing assessment tools and other materials. Collaboration with other agencies is also prevalent, although there is a lack of uniformity between areas. The following chapter will look at satisfaction with service provision and any evaluations that have been carried out.

CHAPTER 6: EVALUATION

Introduction

This chapter presents the findings from the literature relating to the evaluation of services provided for young carers. The formal literature contains few evaluations of services², and to date the research findings remain equivocal, for example the SSI (1996) noted a number of criticisms of local authority social services. They referred to families reporting that they received no services, were not aware of being assessed, feeling frustrated at social workers' not spending time with them, and social workers not adopting a 'whole family' approach. However, Frank (1995) had revealed that most families were 'quite complimentary' about local authority social services (p.33). They described help with cleaning, shopping and physiotherapy, as well as support visits and a telephone lifeline, but the services were generally seen as not frequent or intensive enough.

Some writers describe users' feedback on Projects, normally obtained by people who developed or worked in the Projects. Independent, external evaluations and assessments of outcomes are lacking. Nor has there been much comparative work to describe different types and models of Young Carers Project and assess their respective merits.

Several writers report that young people who attend Projects are positive about the opportunities to share their experiences with others in similar situations and welcome access to adults with whom they can talk over private matters (Frank 1999). The visits and interviews by the SSI (1996) found that young people and their families valued their focus on the child and independent status. It has been found that the leisure activities are the most popular element of young carer schemes (Mahon and Higgins 1995; Becker et al 1995). Individual comments by members of young carers groups indicate a range of benefits, including time out, receiving money and clothes, and feeling respected (Shah and Hatton 1999). Some of those attending Projects see them as a general youth service and do not realise that they are focusing on young carers (Shah and Hatton 1999).

Becker et al. (2001) reported that young carers projects are especially valued by 'those families who resist professional assistance or are not entitled to it' (p. 74). Department of Health research indicates that professionals also value the services provided by the young carers projects, particularly the '*specialist response to the needs of young carers and their families, and as a way of locating appropriate access to statutory services, and raising the profile of young carers*' (p23 Aldridge and Becker, 1998, Surge of Support SSI 1996; Dearden and Becker 2001). However, the SSI noted certain difficulties or dangers in relation to the development of Projects. These included Projects taking over statutory responsibilities, being used as a 'dumping ground' regardless of the young carers' needs and being over-extended.

In a number of instances projects have been set up with funds in place to cover independent evaluations, for example the Young Carers Research Group has

² The SSI Report refers to 'A life of our own', and evaluation of three RHA funded young carers projects by A. Mahon and J. Higgins (1995) Manchester Health Services management Unit

evaluated a number of Young Carers Projects by incorporating the views of parents, professionals and the young people who's needs such services were designed to meet (e.g. Dearden and Becker 1996, 1998b; Newton and Becker1998) Dearden, C., Becker, S., 2000, Listening To Children: Meeting The Needs Of Young Carers in Kemshall, H., Littlechild, R. (Eds.), User Involvement and Participation in Social Care: Research informing Practise, London: Jessica Kingsley. Two of these evaluations are of particular interest here, an evaluation of the Nottingham young Carers project carried out in 1995, and a more recent evaluation involving the Sheffield Young Carers Project carried out over a three year period from 1997 -99.

1. Evaluation of Nottingham Young Carers Project

The Young Carers Research Group (YCRG) at Loughborough University carried out a six-month evaluation of the Nottingham Young Carers Project from June to December 1995 (Dearden, C., Becker, S. 1996 Young Carers at the Crossroads 1996: An Evaluation of the Nottingham Young Carers Project). The evaluation was seen as an essential part of service development by Crossroads, which funded the project.

The aims of the evaluation were to:

- i. Determine whether the project met its own aims and objectives
- ii. Inform future work with young carers
- iii. Ascertain whether or not the project provided value for money.

Data were derived from two sources - quantitative data which had been collected on an on-going basis by the project, and interviews which were conducted with a cross section of young carers, parents and professionals who had referred young people to the Project. Young people and their parents took part in face-to-face interviews, whereas the cross section of professionals from health, education and social services backgrounds were interviewed by telephone.

Findings

A comparison of quantitative data with national figures (Dearden and Becker 1995 Young Carers: The Facts, Sutton: Reed Business Publishing) revealed that the Nottingham Project attracted younger carers than national average. They also included carers over the age of 18 who were not represented in the national figures. Although the figures collected in June were similar to the national figures the December figures showed a higher level of educational problems among young carers involved with the Project than the national figures, 47% and 24% respectively. The percentage of young carers from ethnic minority backgrounds corresponded to the national figures in June; however, the December figures were higher than the national figures, 15% and 9% respectively.

Family support: The Project was child-centred and needs led, however it maintained close contact with parents and other family members and, where appropriate, would assist them in securing services, support and assistance with other agencies. Just over one quarter (26%) of young carers and their families had no outside services other than those provided by the project.

Satisfaction: The evaluation showed that the Project was highly valued by the young carers who used it, their parents and the professionals who referred to it. The comments made by all these people in their interviews indicated that it was not only the Project itself which was highly valued but also the inter-personal skills and qualities of the project worker.

Awareness raising: As part of an ongoing awareness raising programme the project had held individual meetings and conducted large scale presentations to: social work teams; district nurses; health visitors; education welfare officers and teachers. In total, the project worker spoke to over 600 people. The emphasis on awareness raising diminished as the numbers of young carers supported by the Project grew.

Inter-agency collaboration: Inter-agency work had enabled the project to set up a small sibling support group for children with disabled siblings; a young carers befriending service; training sessions with the ambulance service; and respite care via the Trent Crossroads Scheme. Attention was drawn to the fact that the project did not replace any statutory services provision but rather complemented it.

Funding: The researchers claimed that the success of Young Carers Projects depended on adequate funding, and asserted that:

The value of identifying the needs of local young carers has been undermined by health and social services' inability to guarantee continuity and security of funding. (Dearden and Becker 1996 p51)

Conclusions: Although included in the aims of the Project, direct working links with ethnic minority communities had not been established as initially hoped. There was no mechanism for involving young carers in the planning and practise of project work, nor a policy for working with other agencies and no contract or agreements with local authorities. Despite the identification of these weaknesses the researchers considered that the Project, over a 6 month period, *proved to be an unqualified success* (p50 Dearden and Becker 1996)

2. Evaluation of Sheffield Young Carers Project

At the time of the evaluation of the project, Sheffield Young Carers Project was the sole provider of specific and tailored services for young carers in Sheffield. The management committee ring-fenced funding to enable an independent evaluation of the development of the project, which was set up in November 1996, to be carried out. The Young Carers Research Group (YCRG) at Loughborough University carried out the evaluation of the Sheffield Young Carers Project over a three year period from 1997 to the end of 1999 (Dearden and Becker, 2000c). The evaluation involved 41 interviews with project staff, young carers, parents and professionals who had referred young people to the project. In addition to the qualitative interviews quantitative data relating to service users was gathered using referral and monitoring forms. Interviews were carried out with:

Participants	Number
◆ Young Carers	17
◆ Parents	6
◆ Professionals	5
◆ Volunteers	2
◆ Nine members of staff	9 (2 were interviewed twice)

Quantitative data collected were compared to national figures (Dearden and Becker, 1995; Dearden and Becker, 1998).

Findings

Family support: The Project was set up for children and young people; however, staff help to support parents as well where appropriate through advocacy and joint working. The evaluation report concluded that it would be desirable to increase parental involvement in the Project activities.

Satisfaction: None of the young carers interviewed had anything negative to say about their involvement with the project, and the majority expressed particular appreciation of the social and leisure activities provided, especially the residential trips.

Parents also highlighted these activities positively and valued the fact that their children had the opportunity to meet others in a similar situation. Although none of the parents criticised the project some expressed worries concerning the insecurity of future funding.

In general Professionals were positive about the project and expressed their satisfaction with the service offered. However, some professionals criticised the informality of the feedback system - this has since been modified.

Awareness raising: The project was committed to awareness raising and had given presentations to a wide range of agencies, organisations and professionals including the local NHS Trust, Social Services, education, school nurses, careers guidance staff, education welfare officers, mental health, social work teams, and disability social work teams. In addition, meetings were held with key organisations such as local schools and youth projects and local projects for minority ethnic communities.

The rate of referrals to the Project was used as a proxy measure of the success of the awareness raising. It was found that the rate of referrals rose steadily until in September 1998, when the number of referrals was beyond the Project's capacity. This led to the setting up of a waiting list and a system of prioritising referrals according to need.

Referrals: The referral process was quite informal and referrals were accepted by telephone rather than referral form. One of the Project staff members interviewed considered the informal referral procedure as one of the strengths of the Project. All of the professionals interviewed stated that they would be confident in referring others to the project.

Inter-agency collaboration: The Project was committed to working in collaboration with other agencies and organisations in the Sheffield area. Links were established with the youth service, ethnic minority communities and Social Services. The Project had plans to become more involved in the process for assessing young carers and was involved in inter-agency discussion about assessment procedures and the need to clarify the procedure. Although the Project accepted referrals from other agencies it in no way replaces or replicates the role and duties of statutory services. Project staff advocated on behalf of young carers and their families in order to secure statutory support for them.

Funding: The Project was mainly funded by joint finance and the National Lottery Charities Board although additional funds had been secured from a range of other sources. The Project operated a hardship fund whereby young carers could apply for up to £50 as additional support for one-off needs. Although successful in securing funding it was pointed out that if the work of the Project was to continue to progress, a more permanent funding structure would be necessary.

Discussion: The two evaluations presented above used similar methodology. However, one was carried out in six months, providing a snapshot in time, whereas the second covered a three-year period corresponding to the early development of the project. The evaluations of both projects were largely positive. Both supported young carers *and* their families. Awareness raising activities were actively pursued initially and then reduced as the projects approached capacity. Service providers and users expressed satisfaction with the services. At the time of the evaluation the Nottingham Project had not achieved all its objectives, for example it had failed to establish links with the minority ethnic communities. Contact with local authorities and other agencies also appeared to be tenuous, and there was no provision for the young carers themselves to be involved in planning or to take any form of ownership of the project. Nevertheless it was deemed to be an *unqualified success*. It is possible that the aims were not realistic within the timescale, and that these objectives were achieved shortly thereafter – we do not have this information.

The Sheffield project, which was evaluated over a longer period at a stage when work with young carers had moved forward, had established links within the community and with both voluntary and statutory organisations. However, it has to be acknowledged that the government's agenda of promoting joined up policy and inclusive working practices has made collaborative working, if not easy, marginally less difficult.

Dearden and Becker raised two important issues concerning funding. Firstly, if the National Lottery were to become a main provider of funds for projects and voluntary organisations, what would become of the responsibilities of local authorities? (Dearden and Becker, 1996). The second issue that they raised is closely linked to the first, in that it is very difficult to develop services and plan for the future when funding is typically short term.

Funding is an issue that is not easily resolved. Rationing, or prioritising referrals according to need, is prevalent in all service provision. In the case of young carers, awareness raising strategies are being employed to 'identify' young people who may benefit from support, however, as soon as a young carers group reaches capacity, a

waiting list is created. There is a danger of creating a demand that cannot be matched; the range of definitions identified in chapter 2 reflects some of the ways in which this could occur. Providing a service for particular groups of young people, for example those who are affected by mental health problems, alcohol or substance abuse enables organisations to apply to alternative funding sources. However, in other situations the criteria for support may result in some young people failing to receive a service because their need does not match a financially determined level. Estimates of the number of young carers vary considerably; however, in areas where there are low levels of employment accompanied by poor health the prevalence is likely to be far higher than in less deprived areas. In order to avoid waiting lists of young people who are in need of support, innovative services are required. These services need to be flexible enough to support young carers as and when they need it without encouraging them to become dependent on limited provision.

EVALUATION: THE SCOTTISH SCENE

As mentioned earlier, the development of services for young carers in Scotland has lagged behind that in England and Wales. Many of the projects cited by respondents in the postal survey have been set up fairly recently which has implications for the amount of evaluation that has been carried out. Respondents in the postal survey were asked to forward copies of any reports, covering evaluations, audits, etc. that had been carried out to the research team. We received a number of documents including annual reports and more sizeable pieces of research which will be presented below. However, it is important to bear in mind that young carers projects, which are sometimes struggling to provide a minimal service due to lack of resources, are unlikely to have spare capacity, either human or financial, to allocate to research activities. In the current climate where the importance of audit and evidence based practice are increasingly recognised, inadequate funding to cover these activities remains the norm. Much of the research and/or evaluation has been carried out in-house, which raises issues of impartiality. Furthermore the satisfaction expressed by young carers must be treated with caution due to the small numbers involved and lack of rigorous methodology in terms of control groups, or comparisons with alternative methods of service provision.

Recent interest in the allocation of resources, reflecting the government's commitment to ensure that distribution reflects local population needs has drawn attention to the difficulty of ensuring equality of services for people in different geographical areas and sectors of society. In order to address these issues Best Practice Standards have been developed in a number of areas which provide details of the 'standards' a service should achieve, what is required in order to achieve this standard in terms of services/support, and the anticipated outcome for the clients. Examples of best practice may be included. In 1998 NCH Action for Children (Scotland) published Young Carers Standards (Scotland). More recently the Young Carers Partnership in Dundee published Best Practice Guidelines for Voluntary and Statutory Organisations (Hughes, 2000), and the Princess Royal Trust for Carers have developed a Good Practice Guide, funded by the Scottish Executive and due to be available early in 2002. A number of organisations provide Young Carers Charters. The Young Carers Standards developed by NCH Action for Children (Scotland) provide a detailed benchmark against which projects can monitor their progress, and in 1999 NCH Action for Children (Scotland) published an audit of their own project in North Lanarkshire.

However, before looking at the findings of the Audit it is of interest to look at the Standards in more detail.

Standard	Requirements	Result for Young Carers
<p>Project Statement of Purpose There is a written statement of why the Project exists, and it is clear how it links with other services that Young Carers in the area can use.</p>	<p>A clear, simple, and up to date statement of purpose is available in the Project. All members of the staff team know where to find the Project purpose, and they understand the contribution it makes to services for Young Carers in their area. The Statement of Purpose is a part of a Children's Services Plan or another interagency agreement, ensuring it fits with other services, and is rooted in the local community.</p>	<p>That the range of needs being met by the service is consistent with its stated purpose, which is understood by Young Carers and their families.</p>
<p>Commitment to Quality There is an Annual review process that maintains and develops best practice with the inclusion of the views of staff, Young Carers, their families and funding partners.</p>	<p>Standards are shared with Young Carers and their families, together with funding partners and other agencies. Young Carers are asked for their views about whether the service meets standards that have been set. Project managers can produce a business plan that demonstrates the inclusion of views from Young Carers, their families, staff and funding partners.</p>	<p>Young Carers are clear about what they can expect from the service and feel it is reliable.</p>
<p>Information (a) Young Carers and their families receive easily understood information about the service, and what to do if they wish to complain.</p>	<p>Information is provided by staff that is presented in different ways people can understand and takes account of young carers racial, cultural and linguistic backgrounds. Staff take care to explain and discuss the content with young carers and their families. The information tells Young Carers how they can express any concerns, and how they may make a complaint if they wish to do so.</p>	<p>Young Carers know what the service is, when it is available, how it works, and how to complain if they want to.</p>
<p>Information (b) Information that would benefit Young Carers and their families is available to them.</p>	<p>Information is available about medical conditions, welfare rights, benefits, (for themselves and for the person they are caring for) care management, practical help and support. Advice is provided or arranged for families on which benefits they may be eligible to claim. Staff enable Young Carers to be given suitable explanation about the illness of the person they are caring for. Staff enable families to share the reasons behind any changes of help given to the care receiver, when these effect the Young Carer.</p>	<p>Young Carers understand more, and are less anxious about things that worry them at home.</p>

<p>Participation The views of all Young Carers using the service are sought, listened to and taken account of in relation to their own needs, their responsibilities, the services provided, policy development, planning and review.</p>	<p>Project managers enable a staff team to be open to developing different working methods that involve young carers (so that young people and children are not simply expected to learn adult methods). Staff have the knowledge, experience and skills to take account of the religious, cultural and linguistic backgrounds of Young Carers and their families and know when to ask for advice or assistance from interpreters or facilitators. Views and opinions expressed are recorded appropriately and that they include those of all young carers.</p>	<p>Young Carers feel confident about contributing to discussion, because they are listened to and what they say is acted upon, and participation doesn't feel like it meets projects needs, more than their own.</p>
<p>Confidentiality A Young Carer's right to privacy and confidentiality is respected unless staff think that the Young Carer or another child is being harmed, or someone's health and well being is being put at risk.</p>	<p>Staff inform young carer of their right to confidentiality, and its limits and their right of access to information recorded by project staff. If staff decide it is necessary in the best interests of someone's safety, for information to be disclosed, every effort should be made to support them and persuade them to give their consent. If consent is withheld, and staff feel it necessary to disclose information, they tell young carers what information will be given and to whom strictly 'on a need to know basis'. Staff give young carers access to information they have recorded about the. Records are securely filed within the project.</p>	<p>Young Carers feel their privacy is respected by staff, and know that in exceptional circumstances staff have a duty to pass information on to other people even if a young carer does not agree to this.</p>

<p>Child protection Safe working practices are followed, and action is taken if abuse is disclosed or suspected.</p>	<p>Young carers and their families are actively involved in the writing of the project child protection statement the project Child Protection Statement which makes it clear what we do if we believe a child is being harmed and how this links with confidentiality. The NCH Action for Children Code of Conduct is followed by staff. Local Child Protection procedures and NCH Action for Children Procedures are accessible to staff and followed. Staff confirm that they have received induction and training on recognition of child abuse and they know what to do if abuse is alleged or suspected. Staff relate to young carers with respect and understand how differences of gender, age, disability, culture and race require sensitive responses to child protection concerns. Staff are familiar with young carers home circumstances and their caring responsibilities.</p>	<p>Young Carers feel respected and valued by staff and feel safe within the service. They feel listened to and supported by staff.</p>
<p>Access to services Young Carers are able to access a mix of services to match their identified needs and wishes.</p>	<p>Assessed individual needs and wishes of Young Carers are responded to, as far as possible. Different cultural interests are taken account of and provided for. If different members of one family can't agree about who should get what service, the staff concerned try to negotiate an acceptable compromise. Staff work with the providers of other children's services to ensure that they are sensitive to the individual needs of Young Carers and their families and that services are provided in a way that allows Young Carers to use them. Managers ensure the budget available to fund project services matches the statement of purpose. Staff possess the appropriate skills to run the programme of services. Supervision and support is given to Young Carers or ex Young Carers who are involved in providing services, whether as volunteers or paid members of staff.</p>	<p>Each Young Carer feels the services they get are helpful and enjoyable, and their ideas for improvement are listened to, and taken account of.</p>

<p>Advocacy Staff speak out on behalf of individual young carers. This might be individually, to ensure the needs of particular families are heard, or collectively, to make sure that agencies working with families know about young carers, and the rights and entitlements of disabled or ill people.</p>	<p>Managers act to ensure that local Community Care, and Children's Services Plans, Agencies policies, and commissioning practice, takes account of the needs of young Carers and their families. Staff are able to negotiate with other professionals to get the best results for families. Staff are competent at working in partnership with parents and helping to ensure they have access to the full range of statutory services to which they are entitled.</p>	<p>Young Carers have access to all mainstream services and activities that other young people have and feel understood in their community. The voices of Young Carers and their families are heard directly by policy makers, with support from staff.</p>
<p>Equality The service is respectful to all people and works to overcome barriers that prevent participation, welcoming the individual differences of Young Carers and their family members.</p>	<p>Staff receive training in issues of Equal Opportunities and anti-discriminatory practice. Staff can demonstrate competence in working sensitively with the differences of Young Carers and their family members. The service values and projects positive images of those using the service and living in the local community, whoever they are. Discriminatory attitudes or practices by staff are not tolerated and are challenged by other staff and management. Discriminatory attitudes or practices by children and young people are challenged by staff. Projects have developed their own Equal Opportunities Statement with Young Carers and their families which is clearly displayed. Projects develop their own practice guidance for the creation of a sensitive working environment that is respectful and actively works at overcoming barriers to participation. The projects policies, procedures, and guidance reflect the parts of the Children Act 1989 and the Children (Scotland) Act 1995 which require us to take account of a child's racial, cultural and linguistic background. Systems are in place to monitor the ethnicity, culture, religion, disability, age and gender of consumers and staff groups.</p>	<p>Young Carers and their families feel respected, they feel safe and comfortable using the service, and help is given to overcome and difficulties in being understood or being able to use the service.</p>

<p>Education Project staff try to ensure that young carers do not miss out on access to education opportunities.</p>	<p>The value of education is promoted by staff to Young Carers. Project staff work alongside education staff to help them understand the demands on Young Carers and to find creative ways to ensure that their education does not suffer. Staff help to raise awareness and an understanding of disability and illness issues with education colleagues. Staff have worked out ways of dealing with bullying of young carers and put these into action when necessary.</p>	<p>Young Carers know that project staff will help them to pursue an education. Young carers receive any additional support they may require from the educational system. Bullying stops.</p>
<p>Health Project staff work with parents to ensure that Young Carers receive care they need.</p>	<p>Staff are attentive to the health needs of Young Carers and discuss these with them and their parents if appropriate. The project provides information that helps Young Carers understand their own health needs and how to take care of themselves. Project staff and their managers try to influence community health services that impact on Young Carers.</p>	<p>Young Carers feel safe to tell staff if they need help to look after their health. Young carers are looked after themselves, if they are ill.</p>
<p>Personal Choices and Decisions of Young Carers Advice and support is offered to Young carers when they are considering choices about their caring responsibilities.</p>	<p>The anxieties, fears and hopes of Young Carers are listened to and taken seriously by staff. In agreement with a Young Carer, staff arrange an assessment of their needs. Staff enable Young Carers to negotiate with family members the kind of caring tasks they carry out, and the amount. Young Carers wishing to leave home are advised by staff of their legal rights and entitlements. They are helped to think through what is involved in taking this action, and are offered appropriate support. Staff follow the Child Protection Procedure when the actions of a Young Carer places them at risk of significant harm.</p>	<p>Young Carers feel that their right to be recognised and treated separately from the person they have caring responsibilities towards is respected, together with their right to self-determination and choice.</p>
<p>Working with parents Staff establish positive relationships with parents of Young Carers.</p>	<p>Managers ensure all staff receive disability awareness training. Time is taken by staff to build confidence and trust with parents. Information is made available to parents about the purpose and standards of the service. Staff do what they can to help parents to receive their entitlements to benefits and the support they need to provide for their children.</p>	<p>Parents feel confident to ask for help if necessary, and they receive proper assistance from the main services.</p>

<p>Working with young carers Young Carers are related to as young people first, and are respected for the caring responsibilities they undertake.</p>	<p>Staff approach Young Carers with sensitivity and understand that they may be apprehensive about sharing information, or identifying themselves as young carers. Time is taken by staff to build trust with individual Young Carers and between members of groups. Staff work with Young Carers to create an environment that is welcoming, safe and fun. Staff are credible with Young Carers by being knowledgeable about local youth culture, and the interests and concerns of young people. Relationships and activities are designed to build self-confidence and self-esteem of Young Carers. Young Carers have an active say in the content of the activities programme. Staff pay attention to the informal times with Young Carers when they may share personal thoughts and feelings.</p>	<p>Young carers are able to enjoy a choice of activities in an environment when they feel accepted and supported.</p>
<p><i>Taken from NCH Action for Children (Scotland) (1998) Young Carers Standards</i></p>		

Perusal of the above Standards reveals that they provide a framework against which organisations can measure their own performance. They include examples of best practice (not included here) and the optimum outcome for young carers. However, standards of this nature can be quite daunting to organisations which may be some way from achieving *any* of the standards in full let alone *all* of them. While they may represent an ‘ideal model’ for service providers to aspire to, for some they are so far removed from reality that they may be ignored. Even the language in which they are couched could result in small projects with few resources feeling that they inhabit a different world.

In 1999 NCH Action for Children (Scotland) published the findings of an audit of the North Lanarkshire Young Carers Project which they organise. The audit was carried out by NCH Action for Children (Scotland) in conjunction with social work in order to consider and evaluate the 15 standards and prioritise them in terms of relevance and importance. Because of limitations on the time available it was decided to focus on four main standards: i) Information, ii) Participation, iii) Access to services, and iv) Personal Choices and Decisions of Young Carers. These four Standards were deemed to be representative of the Project’s overall performance. Questionnaires were developed for young carers, staff, and parents in contact with the Project. The young carers and staff completed the questionnaires as part of an interview; parents were sent a postal questionnaire. Documents were also reviewed and a sample of case files examined in detail. The four standards were all met, however a number of interesting points were raised:

Information (a) *Young carers and their families receive easily understood information about the service, and what they do if they wish to complain.* Some parents seemed uncertain about how to complain should

they wish to, but as this had not occurred this was not deemed to be an issue.

Participation *The views of all young carers using the service are sought, listened to and taken account of in relation to their own need, their responsibilities, the services provided, policy development, planning and review.* However, it was acknowledged that young carers were not really interested in policies and procedures, and as such participation is primarily in terms of ‘having fun’, rather than influencing how the project develops.

Access to services *Young Carers are able to access a mix of services to match their identified needs and wishes.* An ‘Assessment of Needs Form’ is used as a means of selection for, and matching within the project. It was noted that a number of young carers had not had a review for some time. Because the service is needs led, a gap in review could potentially impact on planning. Although it was outwith the scope of the audit to elicit comment from local authorities and other agencies, referrals received from Social Work, Health Visitors, schoolteachers, and directly from parents were taken as a positive indicator of the service provided.

Personal Choices and Decisions of Young Carers *Advice and support is offered to Young Carers when they are considering responsibilities.* Staff members indicated that in general young carers did not discuss their caring role in detail, that in many cases the main benefit of the young carers project was being able to socialise in the company of other children who can understand their experience.

The audit concluded that regular reviews were necessary. The report acknowledged that, while the project is successful in engaging with the young carers who appreciate the services provided, they were less clear about their progress as advocates at a macro authority level. Attention was drawn to the differences in understanding regarding the situation of young carers amongst some organisations and the importance of developing a full Young Carer’s Strategy for the Authority. Finally the importance of Child Protection was highlighted, however, staff were concerned that if this aspect of the project were over-emphasised it could be counterproductive as young people might view them in a similar light to social work which they believe is seen as potentially threatening.

What is particularly interesting about the findings of the above audit is that project staff, young carers, and their parents were all involved in the process, and that the Standards provided a robust framework within which to evaluate the services. Disparity between the ‘ideal’ and their current situation formed the basis of recommendations for the future.

Evaluation of a pilot project

Another evaluation taking a relatively rigorous approach focussed on the development and progress of the West Lothian Young Carers Project Pilot which was set up in March 1999. The project grew out of a partnership between West Lothian Council,

Lothian Health, West Lothian Healthcare NHS Trust and Carers of West Lothian. It was decided that the pilot project should not be highly publicised in order to avoid creating unrealistic expectations amongst young carers in the area, and ten young people aged 11-16 were selected through the existing networks. The evaluation was based on the 'Achieving Better Community Development (ABCD)' approach, which the authors suggest is a useful way to measure the impact and effectiveness of support offered. The ABCD approach involved focussing on a) stakeholders, including participants, their families and service providers, b) inputs e.g. funding, staff input, information, c) processes i.e. the way in which inputs are used to achieve intended outputs, d) outputs, e) outcomes, f) measures, and g) indicators (proxy measures).

Reported positive outcomes included high levels of participation, increased confidence and independence, reduced levels of stress, increased social involvement outwith caring responsibilities, improved educational attainment and attendance, the development of group skills. Negative outcomes included over dependence with some of the participants having difficulties where the group ended. For workers positive outcomes included increased knowledge and understanding, and the development of links with other relevant organisations. The project secured further funding and the staff attribute their success to the approach they have adopted which has involved encouraging young people to be involved in the decision making, supporting each other, organising events e.g. a conference, and presenting inputs to various professional gatherings.

A more recent report from West Lothian was published in July this year (Boyle, 2001). This report was commissioned by Carers of West Lothian to explore how young carers in West Lothian could continue to be involved in developing support initiatives for themselves and other young people who take on caring roles.

The report presents the findings of a consultation process involving 17 young people in addition to information derived from an interview with a guidance teacher interviewed as part of the evaluation. Although only one teacher was interviewed the comments are of interest. The interviewee reported that it is difficult for guidance teachers to know if a pupil is a young carer. They also noted that there might be difficulties in prioritising young carers issues over other issues within schools. However, they indicated that if a young person's performance or study time has been affected because of their caring role the school should alert the exam board.

Consultation with the young carers revealed that:

- ◆ Most respondents felt that guidance teachers should play a major role in providing support.
- ◆ Respite was particularly important
- ◆ Advocacy, particularly between parents and young carers would be welcome.
- ◆ Activity based clubs, residential trips, individual support and befriending were appreciated.
- ◆ Guidance teachers were perceived to be supportive, however other teachers were often unaware
- ◆ Many young people had negative attitudes towards social work
- ◆ Health professionals were rarely mentioned

The report drew attention to the importance of raising awareness, suggestions included training for professionals and young carers themselves, written information, providing support in schools, and holding conferences. However, the problem of achieving a balance between raising awareness and retaining privacy was highlighted.

Annual reports

Several respondents provided us with copies of annual reports, newsletters, and 'updates' prepared for group members and other interested parties. Annual reports typically include information about the development of projects and activities. In many cases new groups or increased membership were reported in addition to an expansion of services where appropriate. The development of carers packs, assessment forms, and awareness raising materials were detailed, and in some instances the findings of evaluations. Evaluations are carried out in some groups, often on a regular basis, by asking young carers, parents, and staff to complete short evaluation forms. While user satisfaction and the feeling of ownership that such participation can engender in individuals are important, comments may be specific to particular groups. However, some findings may be common to young carers in a number of groups:

- ◆ Some children find discussions difficult to cope with, making the balance between discussions and leisure activities difficult to manage.
- ◆ Friendships made in groups are particularly important, perhaps more important than the activity involved.
- ◆ Being able to talk to someone who knows about young carers' home situation is useful
- ◆ Information pertaining to specific conditions is appreciated
- ◆ It is important to be able to trust staff (participants in one study reported that social workers were present in a group they attended and they felt that they had to 'watch' what they said.)

The Dundee SIP Young Carers Partnership reported that all their enquiries are logged and monitored. Thus all new young carers referral/enquiries on file will be part of a continuously updated system which can assess the impact of the Young Carers Partnership on the referral. They are committed to developing appropriate research and to complying with Scottish Executive Monitoring and Evaluation. However, they have acknowledged the skills required to achieve this and the possible conflict of interests inherent in in-house evaluations. A comprehensive report covering the first year was prepared by Public Health Medicine and published in March 2001.

General research

The majority of the reports received related to evaluations and/or estimates of prevalence. However, Fife Young Carers (FYC) provided us with details of a piece of research which was carried out with a view to providing information to support the further development of services for young carers (Centre for Health and Social Research, 2001). Following a successful submission to the National Lotteries Charities Board FYC commissioned the Centre for Health and Social Research (2001) to carry out the project.

Participants: Eleven former young carers, 3 male and 8 female, aged 17-30, were interviewed.

- ◆ Seven had been primary carers
- ◆ Two were still caring.
- ◆ Four were daughters, two were sons, four were siblings and one was the granddaughter.
- ◆ Six were in employment, five of whom were in caring work, three were students.
- ◆ Eight felt that their educational achievements had been affected.
- ◆ In three cases the school had been aware of the situation – the other young carers felt unable to inform the school although they indicated that they would have welcomed a proactive approach from teachers.
- ◆ The majority felt that their social life had been adversely affected – several did not tell their friends.
- ◆ Most *had* received practical support through the statutory and voluntary agencies.
- ◆ Most would have liked someone to talk to.

Suggested support included:

- ◆ Ways to facilitate self-recognition
- ◆ Provision of information
- ◆ Helpline for young carers
- ◆ Increasing awareness amongst professionals
- ◆ Further extension of young carers groups.

This piece of research involved nine young people who had been carers in the past, and two who were still caring. Although most had received practical support from statutory and voluntary agencies they reported that they would have liked to have someone to talk to. Eight participants felt unable to inform the school of their home situation, however, they now felt that they would have appreciated a proactive approach from their teachers. This type of information, derived from former carers who are able to view their previous situation with hindsight, is particularly useful. It is also reassuring that they would have welcomed some of the support which is typically offered by the majority of young carers projects today.

Conclusions

The importance of evaluating services cannot be over-emphasised. The planning and development of support for young people who take on a caring role should be based on up to date information relating to the number and distribution of those in need of support, and reflect the needs and preferences of those who will use them. The disparity between areas is a cause for concern and should be addressed by all authorities. The Standards developed by NCH Action for Children (Scotland), Action for Carers, and the Good Practice Guide due to be launched by the Princess Royal Trust for Carers next year will provide a benchmark against which services can be measured. Local authorities, health boards, education, and voluntary organisations need to work together in order to provide an appropriate level of support for young carers in all areas of the country.

CHAPTER 7: CONCLUSIONS

Overall approach to the needs and rights of children with a disabled family member

Any discussion of ‘young carers’ needs to acknowledge that the concept is contested and that there is a spectrum of viewpoints. At one end of the continuum are those who are fully committed to providing separate services for children and young people to provide relief, support and reduced stress. This is seen as a response to children’s needs (both externally and self-defined) and to the wishes of ‘young carers’ that the researchers and workers are in touch with. At the other end of the continuum are those who argue that the main priority is to provide practical, caring and other support to disabled parents, so that the need for children to be young carers is reduced or avoided. Some believe that attention and resources has been diverted from disabled parents through the growth of the young carers’ movement

There is an increasing willingness to try and find common ground with a ‘family’ focus, which recognises the importance of providing services to parents and of giving children a voice and, in some circumstances, separate attention. However, there remain strong ‘camps’ which mainly emphasise services for parents or for children.

Definitions and conceptualisations

The term ‘carer’ became prominent in the 1980s to give status and positive connotations to adults who were previously ignored and not recognised. This does not fit well with children, for whom the role is disapproved and seen as undesirable. Indeed definitions tend to incorporate the idea that young carers are those who have assumed *inappropriate* roles or levels of domestic responsibility. On the other hand a ‘family’ discourse risks assuming an identity in all instances between children’s and parent’s interests.

The concept of ‘young carer’ was initially developed largely in relation to children with a parent who has a physical impairment. In such families the ‘young carer’ undertakes ‘significant’ personal care tasks towards the parent and/or carries out other household activities that the parent is not able to do. In keeping with the widening concept of disability in legislation, young caring has been extended to encompass circumstances where parents have a range of issues – physical impairment, chronic or terminal illness, mental health problems and dependency on alcohol or drugs. It has also been recognised that children may take on a caring role with respect to other family members, particularly their brothers, sisters or grandparents. At the same time, it has been recognised (as in the Children (Scotland) Act 1995) that children may need help because they are adversely affected by disability in the family, although this may not entail caring in the sense of looking after someone or the household.

Most definitions recognise that both ‘caring’ and ‘adverse effects’ occur along a continuum. A crucial distinction is often made between a *sole or primary carer* (where the child is the only carer as no adult is available) and *supportive or secondary carer* (where the child assists an adult). When a child is caring for a sibling, this is nearly always in a supportive role.

A survey of over 2000 young people attending young carers projects found that rather more were girls (57%) than boys (43%) and just over half (54%) lived in lone parent households. Many were aged under 12 (Becker et al 2001).

The inclusiveness of people needing care

Increasingly 'young carers' have been seen to be those providing care or support to disabled people in the widest sense (embracing mental health problems) and also parents with addictions and serious or terminal illnesses. This inclusiveness is partly meant to recognise the needs of children (and parents) where the issue prompting care needs is most stigmatising and also seen as less deserving, because it is related to life-style and can be perceived as self-inflicted. Some young carers services have responded by providing open access to children in any type of caring situation, while others focus on those in one specific type of circumstance. Some children attending projects do not have a caring role, but are thought by professionals to be affected emotionally or socially by having a disabled family member.

Legislation

The legal duties of local authorities to young carers are contained in legislation related to disability, community care and children. The legal responsibilities towards children are often interpreted in ways which see them as individuals separate from their families or as victims of family circumstances. Community care legislation likewise has an individual emphasis, with the result that the needs of disabled people as parents are often not acknowledged. The interplay between the different pieces of legislation has led to some anomalies and uncertainty related to definition, assessment and service provision. The legal position with regard to children's entitlement to an independent assessment has been unclear as it relates to Scotland. This will be clarified by the implementation of the Community Care and Health (Scotland) Act 2002. The concept of 'Children in need' is seen as stigmatising in England, so there has been some resistance to using this category as a 'ticket' to gain access to services. In Scotland, children in need explicitly includes children 'adversely' affected by disability in the family, which may be interpreted to include some or all young carers.

The published literature

Much of the research and wider literature has focused on the needs of young people and descriptions of services. Relatively little systematic attention has been given to the processes by which children do or do not come into contact with agencies or in relation to the assessment process. Few external evaluations have been carried out on Projects or other kinds of service.

The views of young people who might be considered as carers have not been obtained on a wide scale. Many of the key ideas about young carers derive from small scale studies carried out in the early 1990s, reinforced by feedback obtained from young people by Project workers and others.

After the initial 'uncovering of young carers' by the early research, 'knowledge' has largely been based on children and young people who attend Projects. This means that little is known about the perspectives of 'young carers' not in touch with Projects.

Also some of the people attending Projects are not ‘young carers’ even by the widest definition.

Identification processes

The ways in which agencies identify young carers is affected by the complexities of definition outlined in the previous section. The notion of ‘young carers’ is not one that came from children themselves, but was created by certain adults who were concerned on behalf of children. Similarly, children and young people have not expressed a demand for services, so active processes are required to identify and locate them. The willingness of children to attend young carer projects indicates that these do accept they have needs to be met, which may be recreational, social or emotional. On the other hand, evidence indicates that most do not like the term or identity of ‘young carer’.

Agencies may identify *populations of young carers* (in order to plan or improve services) or *individual young carers* to assess their needs and perhaps encourage them to take up a service on offer. Aggregate identification is hampered by definitional difficulties and the varied forms in which agencies hold relevant statistics.

Little is known about how young carers come to the attention of local authorities. The literature includes many statements that adult services tend not to notice or heed children's needs, while children's services usually get involved in extreme cases, where there are child protection concerns. Young carers’ Projects usually recruit children initially by promoting awareness of the service among social workers, health professionals and teachers. One Scottish Project identified 31 young carers in this way, of whom only 3 were primary carers. The agency survey showed that, once established, the majority of projects receive self-referrals and referrals by parents.

Both the literature and the survey indicated that a number of Projects have difficulties in acquiring a large number of referrals, which is attributed in part to parents’ unwillingness to give consent on account of various inhibiting factors. Research has indicated that children and/or their parents are often reluctant to seek help for a variety of reasons, including a wish for privacy, feelings of stigma and fears about community or professional responses. Others are simply unaware they may get help. It has also been suggested that identification of young carers is inhibited by ignorance among professionals in contact with the families and the views of some professionals that young caring is outside their remit.

Needs assessment

Young carers research and feedback from young people attending Projects has indicated that they have four main needs. These are for:

- information (e.g. about their parent’s condition, services)
- individual support or counselling
- practical assistance
- social contacts and recreation

The disability rights perspective, in contrast, emphasises that the main need is to prevent or stop young caring by means of financial, practical and other support to the whole family.

Holistic assessment frameworks have been advocated for use by statutory and voluntary agencies. These promote integrated attention to the child, parenting capacity and the wider environment.

Children in Scotland who are 'adversely affected' by disability may be assessed as children in need. From 2002, they will be entitled to request their own assessment under community care legislation. Evidence from England indicates that few young carers (perhaps 10% of those identified by projects) have independent assessments of their needs carried out by local authorities. When this does happen, the children do not usually have a good understanding of the purpose of the assessments, but positive help to the family sometimes results.

Research on sole or primary young carers indicates that not uncommonly their school attendance or performance is affected by their caring role, but there is little evidence of concerted efforts by education authorities or schools to tackle this.

Referral procedures to many Projects are informal and brief, though some have extensive and standard formats. A minority of Projects have developed with their local authority a protocol for assessment. Several use pictorial questionnaire booklets or other tools to aid identification and joint assessment with young people. It appears that, at least in some cases, assessments are service led (i.e. to assess suitability for attendance at a Project) rather than needs led.

Service approaches

Attitudes about actual and desirable service approaches reflect different interpretations and emphases with regards to children's rights, disabled people's rights and the extent to which children, young people and parents are perceived as autonomous individuals or family members. In the 1990s, service development was largely based on the principle that children and young people needed and were entitled to have access to a separate, dedicated service away from home. This was sometimes supplemented by support to parents and advocacy. Recently attempts have begun to shift the focus to an integrated 'whole family' approach.

Specific services

Services (and to some extent the legislation) are fragmented, with significant divisions between adult and children's services. All the following are relevant but tend to operate with little regard to the other:

- local authority community care and children's services (and schools)
- the Benefits Agency and national income support organisations
- Young Carers Projects (nearly all in the voluntary sector, though often funded directly or indirectly by local authorities and/or health boards)
- Special Initiatives like SIPS and Sure-Start
- Health Services

Most information is available about young carers projects, the great majority of which are provided by voluntary organisations. A few are one-off projects developed to meet local needs, but most are run by larger organisations concerned with children, disability or mental health. These include the Princess Royal Trust, Barnardo's, the Children's Society and Crossroads. Many projects have developed in response to local initiatives, so their availability is piecemeal. Many Projects have small-scale and short-term funding. Therefore they find it difficult to recruit and retain staff and 'clients'. Access and transport is a significant issue, especially in rural areas. Whereas some Projects in England are well-established, most in Scotland were set up very recently.

Projects normally focus on children and young people, though a minority also involve parents. Some are *generic*, in that the young caring of service users may arise for any of several reasons or might relate to any household member. Others are *specialist*, concentrating on particular circumstances, such as children with parents who have a mental health problem or misuse alcohol, or those caring for siblings. Age and other criteria for admission vary widely. Some Projects offer places indefinitely, while others have time limits.

Projects typically provide three kinds of intervention:

- group activities and discussions
- individual counselling or befriending
- advocacy on behalf of the child or family

The majority appear to concentrate on providing opportunities for enjoyable interaction with peers. This can serve as a trust-building basis for access to individual counselling.

Very few Young Carers Projects involve parents on a significant scale, though their permission is usually needed for young people to participate. Exceptions include Dundee (siblings project) and Bournemouth. Many Projects provide relatively long-term activities, support, counselling etc. This provides continuity for the children, but reinforces their separate identities and means there are few vacancies for new children to join. A minority of projects act in a short-term way to help young people link in to informal networks or mainstream services (e.g. to help with transport or social activities).

Much less information was available in the literature and from the survey about the nature of local authority and health service provision. Evidently the statutory services are sometimes providing services to parents with care needs and the availability of these services will impinge on their children. Commentators have pointed out that the paucity of support to parents who are chronically ill or disabled helps create or sustain young caring. Views differ on whether devoting resources to young carers projects is a necessary response to what is perceived as the inevitable shortfall in support to adults or contributes to that deficiency by diverting attention and money.

Some local authorities and health services provide funding for young carers projects and individual professionals refer children to the projects. Also a small number of councils have appointed staff or set up their own Projects with a focus on young

carers. It appears that most local authorities do not provide information about services or promote understanding of services. Direct payments have considerable potential to alleviate the circumstances of families with young carers, but little is known about their impact on children.

In recent years, co-operation between agencies has grown, but is still thought by many people to be inadequate. At a national level, young carers projects share ideas through their own network and the Carers National Forum, while at local level some joint initiatives have developed.

Evidence about success

Apart from feedback by service users, little evidence exists about the effectiveness of services for young carers and their families. A few short-term evaluations of particular projects have been carried out, either internally or by the Young Carers Research Group. Studies have examined satisfaction by key stakeholders, but not assessed outcomes or compared different strategies. No evidence appears to be available about the impact on young carers of interventions which aim at supporting their parents or siblings.

Young carers projects are generally successful in attracting children and young people, many of whom value the social and recreational activities. Some young people also report how helpful it is to have an independent person they can share their concerns with. Two evaluations in England indicated that planning and service development included little participation by young people, although an audit by NCH Action for Children (Scotland) in Lanarkshire found that young people's views were obtained and seriously attended to. Several Scottish reports of user feedback highlight young people's gains in friendships and reduced stress.

Conclusions

There is broad agreement that it is inappropriate for children to assume major responsibility for personal and emotional care or domestic duties, when their parents' capacities to undertake these are restricted. Actual and advocated policy and service responses to situations where this occurs are contested, however. Different approaches entail targeting parents, children and young people, the family as a whole or combinations of these. The differences reflect fundamental divergences in view about such matters as the nature of childhood, families, disability, mental health problems and rights, though some attempts are underway to establish common ground.

The main service development has been the development of projects which mainly offer individual and group activities and support for children and young people outside the home. These are generally enjoyed and valued by the young people who attend. Some parents regard the projects positively, but it seems others are unwilling for their children to be involved.

Many young carers have no project near to them, resulting in geographical inequity of access. Moreover the Projects help children cope with young caring and do not tackle the reasons for young caring. They are normally not closely linked with other mainly statutory services aimed to ameliorate family circumstances or empower parents. The

continuing existence of many young carers indicates that financial, practical and other services for adults with disabilities or other difficulties are inadequate. Not only is there a lack of co-ordination between voluntary and statutory agencies, but within the latter there appears to be a fissure between adult and children's services and limited co-operation between the various kinds of professionals involved (notably social workers, health professionals and teachers).

Services for young carers are a prime example of the need for concerted efforts by different agencies and professions to develop a shared approach and provide coherent services based on holistic assessments, as promoted by the Department of Health *Assessment Framework* and the Scottish Executive *Action Plan*³. It seems desirable to have a common strategy at central and local government levels in Scotland to promote a well co-ordinated programme of interventions aimed at reducing the need for children to be sole or major carers, while ensuring that children do have access to separate, confidential support where this is required.

Research is necessary to identify more clearly the spectrum of caring responsibilities undertaken by children within families covering households with and without a parent or child who has a disability. There is also a need for independent evaluations of assessment processes and service provision. It is important to assess the impact of measures such as Direct Payments and practical and respite services for disabled adults and children.

³ Launched on 31st October 2001

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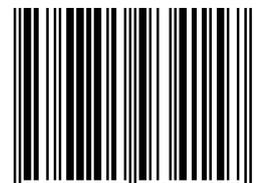
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