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Young Carers: Assessment and Services Literature review of identification, needs assessment and service provision for young carers and their families

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A literature review was undertaken to examine how voluntary and statutory agencies identify, assess and provide services for young carers and their families. Analysis of published work was supplemented by a survey of relevant organisations, assessment of agency documents and a small number of interviews with experts.

Main Findings

- A fundamental divide exists in views about young carers projects. They may be seen as a positive response to children's needs and rights or as a diversion from adequate support to parents that would enable the extent of young caring to be reduced.
- The published literature provides considerable information about the nature of young carers projects, but there are important gaps concerning statutory provision, assessment processes and evidence about the impact of different approaches to services.
- Awareness among professionals about young caring has grown considerably, but there is still evidence of ignorance and a lack of interest among certain key professionals.
- Some young carers and their families are reluctant to engage with services for reasons of privacy, stigma and fears about community and professional responses.
- Only a small proportion of young carers have had their needs assessed. Children's understanding of assessment entitlements and procedures is very limited.
- Holistic frameworks have been promoted for assessing young carers' needs, their family and environment, but in practice assessments are often superficial and narrowly focused.
- Typically, young carers projects offer group activities and individual counselling or befriending for children and advocacy on behalf of the child for improved family services. Those who attend projects enjoy them.
- An integrated inter-agency approach is required.

Aims of Study

The objectives of the study 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.

Methodology

The primary element of the research was a **literature review**, focusing on recently 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).

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 certain children as 'young carers'
- 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.

Consequently, the literature provides few and largely incidental accounts of the issues which were the subject of this study, except for approaches to service provision. Few external evaluations of services have been undertaken.

Definitions and legal duties

The full report discusses the way in which the concept of young carer has developed and outlines relevant legal definitions. 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. Some writers and certain of the interviewees have challenged either the basis or the usefulness of the concept of young carers.

Identification processes

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. 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. Research has shown 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. Identification of young carers

is also inhibited by some professionals having little awareness about young caring or seeing it as outside their remit.

Needs assessment

Research on young carers 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 that address the needs of the child, parenting capacity and the wider environment have been advocated for use by statutory and voluntary agencies. Children 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 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.

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.

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 tons concerned with children, disability or mental health. 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.

Projects typically provide three kinds of intervention:

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

Much less information is available about the nature of local authority and health service provision. 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. 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. Direct payments have considerable potential to alleviate the circumstances of families with young carers, but little is known about their impact on children.

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 examined satisfaction with the service, 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.

Those who attend young carers projects generally 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. Young people also describe making new friendships and feeling less 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. However, views differ as to whether the best policy response is to target parents, children and young people, the family as a whole or combinations of these.

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.

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 scope for much better co-ordination between voluntary and statutory agencies, between adult and children's services and among different professionals. Common holistic assessments would be helpful.

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 needed, for example, to provide independent evaluations of young carer projects and assess the impact of measures such as Direct Payments and practical and respite services for disabled adults and children.

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