

Literature Review to Inform
the Inspection of Social Care
Support Services for Carers of
Older People in Northern Ireland

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FOREWORD

LITERATURE REVIEW

This literature review of carers services has been produced to inform the development of standards for the Social Services Inspectorates Inspection of Social Care Support Services for Carers of Older People. The aim of the inspection is to evaluate support services across the 4 Health and Social Services Board areas against draft standards which have been developed after comprehensive consultation with the statutory, voluntary, education and private sectors. Particular attention was paid to ensuring that both individual carers and carers' groups were central to the consultation process and informed the draft standards development and the inspection process.

The literature review highlights the historical development of services for carers, examines the extent of caring and looks at both national and international developments over recent years.

In particular it identifies what carers value, which should inform the development of services within both the statutory and voluntary sector and enhance support for carers in their important and invaluable caring role.

PAUL MARTIN

Chief Inspector

DEFINITIONS

Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people who care for another family member.

Caring is an issue that can affect anyone at any time irrespective of job or status and every caring situation is unique. Many carers would not identify with the term 'carer', rather they see themselves as dutiful parents, sons, daughters, partners or friends accepting and discharging a responsibility toward a friend or loved one. For the purposes of this review caring is understood to be the help and support provided without payment by individuals to a family member or friend.

LITERATURE REVIEW TO INFORM THE INSPECTION OF SOCIAL CARE SUPPORT SERVICES FOR CARERS OF OLDER PEOPLE IN NORTHERN IRELAND

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Introduction

The focus on caring is relatively recent both in terms of social policy emphasis and practice developments. In fact, it is only fairly recently that caring has been recognised and researched as a concept in its own right. Some progress has been made in acknowledging carers' experiences, their needs and in establishing legislative rights to assessment and service provision. In some respects the United Kingdom can be seen to have been progressive both in establishing rights for carers and in its desire to also involve carers in the planning and delivery of services designed to meet their needs. However, the implementation of Valuing Carers : A Strategy for Carers in Northern Ireland (DHSSPS 2002) will involve challenges in balancing the needs of the carer and the cared for person and the resources implications. Similarly, the speed and incremental nature of change involved in the development of agency/carer partnership needs to be acknowledged. Issues such as these are important both in terms of fully involving carers but also in ensuring the appropriate outcomes are reached through engaging in the dynamic process of involvement itself. This is an important process, which needs careful and continued attention by agencies, if long lasting and sustainable arrangements are to be achieved.

Historical development

Caring as a term only began to appear in the literature in the late 1970s. Prior to this, its invisibility was due to the pre-dominance of two different and opposing perspectives of family life. One philosophy suggested that caring was just part of family life and kinship. Early academic studies, which highlighted the importance of the extended family and kinship in the East End of London, supported this perspective (Young & Wilmott, 1957). The other contrasting view proposed that caring was an activity with which families were no longer concerned. This perspective gained credence from alternative research studies, which suggested the emergence of a modern nuclear household, and a family that had fractured kinship networks. This view proposed that families were no longer able to provide care for family as they had in the past. Both views together served to ensure that caring, as a distinct concept was not recognised and remained invisible to researchers and policy makers until the late 1970s.

Feminist writers in the late 1970s and early 1980s began to contest simplistic interpretations of family life and the increasing emphasis in public policy on community care. Care in the community had become a recurrent strand of government policy since the 1960s. Its popularity appeared to be based on an assumption that carers, many of whom were women, were ready to be mobilised as a “new reserve army of unpaid labour” (Twigg & Atkin, 1994, p3). This was challenged somewhat by the 1985 General Household Survey, (GHS), which indicated that significant numbers of spousal carers were in fact male.

Much of the early research focused on the extent and impact of caring and as a consequence highlighted how common caring was. Caring as a generic term encompassing a range of activities and relationships, emanated in the 1980s and was first defined in the dictionary in 1984 (Pahl, 1994 in Heron, 1998). Many carers however, did not recognise themselves as carers preferring the term “relative” which for them captured the perspective that caring was an extension of the role of the family. Nevertheless, the real strength of the generic term “carer” lay in it being utilised by the emerging carers lobby, (what is now Carers UK), who began to bring pressure to bear on government to recognise carers as a distinct group of the population with commonality of need and to acknowledge them in the rhetoric and reality of social policy.

Thus it can be seen that the recognition of caring by governments and indeed by some carers themselves is a developing and relatively new area. This is also the case internationally. One of the main challenges of the concept of caring is how to convey the complexities of individual caring into a definition, which is all embracing yet meaningful. Clarity is required regarding what constitutes caring to enable carers to identify themselves and for agencies to correctly identify and respond appropriately to carers’ needs.

Definitions of carers

It is therefore hardly surprising that no simple and universally accepted definition of “carer” exists and that existing definitions have tended to be all embracing in nature. Consequently, while they provide a generic perspective on caring and a starting point from which to focus the discussion of caring, they tell us little specifically about who carers are and what they actually do. For example one definition defined a carer as “anyone looking after a partner, relative or friend because of an illness, old age or disability, who may not be able to manage at home without help” (Warner & Wesler, 1998 p7). This does not however indicate the amount, duration or type of assistance given by the carer nor the relational aspect of caring.

Valuing Carers¹ probably provided the clearest, global definition to date of what constitutes caring and by whom. It defined carers thus: “Carers are people who, without payment, provide help and support to a family member or friends who may not be able to manage at home without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people under 18 who care for another

1 DHSSPSNI (2002) *Valuing Carers: A Strategy for Carers in Northern Ireland*. DHSSPS: Belfast. P6

family member”. This gives an indication of the unpaid nature of caring, the possible relationships which may exist between the carer and the cared for person and that caring is not the prerogative of the adult. However, within this a great variety of activities exist in terms of the range and nature of assistance given by carers and its duration.

Extent of Caring

In Great Britain, 5.7 million people classified themselves as carers, a figure which represented 13% of the population (General Household Survey, GHS, 1995). Approximately one-third of these were co-resident carers, two-thirds were caring for 20 hours per week and a staggering 855,000 (15%) were providing care for 50 hours or more per week. Co-resident carers were found to be providing high levels of personal and practical care with personal care being the type of care most often associated with high dependency. A family member most often provided care, with nine out of ten carers caring for a relative (GHS, 1995).

In Northern Ireland, the 2001 Census asked specific questions about unpaid, caring responsibilities, for the first time. These were defined as “looking after, giving help or support to family members, friends, neighbours or others because of a long-term physical or mental ill health or disability or problems relating to old age”. The 2001 Census found that there were 185,066 carers in Northern Ireland, representing 11% of the population here. Previous estimates had suggested that there were in the region of 250,000 carers, closer to 14% of the population (Health & Social Well-being Survey, 1997). Moreover, the Northern Ireland Household Panel Survey (NIHPS) (2001) found that 16% of its respondents identified themselves as carers. The Census response rate of 95% of the population probably explains the differences noted as 5% of the population equates to some 80,000 people who did not respond. When this is considered, other estimates such as NIHPS (2001) may be more accurate.

Furthermore, given the high incidence of disability within Northern Ireland, one might expect that proportions would equate to that of other parts of the United Kingdom. Regional variations were noted within Northern Ireland with 10% of respondents in the Western Health and Social Services Board area identifying themselves as carers and 12% in the Eastern Health and Social Services Board area (Census, 2001). Differences in findings are small but highlight the difficulty in identifying carers from their sense of “normal” obligations.

In Northern Ireland, 38% of carers were found to be co-resident, 17% were caring for up to 19 hours per week and 12% were providing care for 50 hours or more per week. Other studies have suggested 21% (Continuous Household Survey, {CHS}, 2000) and 25% (Census, 2001) of carers were involved in intensive caring. The majority of carers are family members with 91% involved in caring for a relative (NIHPS, 2001).

Characteristics of Carers

It is important to acknowledge that carers are not a homogenous group. However, pertinent themes emerge in a review of the literature, which warrant discussion as they inform both the identification of carers and the development of appropriate services.

Age

Age is a pertinent factor in caring, as most carers are in late middle age or older people themselves, for example, 54% of carers in Northern Ireland are 45 years or older with 21% over 60 years old (NIHPS, 2001). The peak age for caring is between 45-64 years (GHS, 1995) and 56% of carers in Northern Ireland are between 45-64 (CHS, 2000). There is relative consistency of this finding across the United Kingdom.

In the literature, there has been an increasing emphasis on the growth in numbers of both young carers and older carers. In terms of older carers, who have been defined as those carers over 65 years, often they are caring for spouses of a similar age or middle-aged offspring, for example, Evason (1995) found 34% of carers in Northern Ireland are aged 60 years or older and 13% are aged over 70 years. This equates with other findings that at least a third of older people can expect to become carers during their retirement (Wenger, 1989). With respect to age and race, some small-scale studies of ethnic minority carers have also found the majority of carers (50%) to be aged over 65 years (Wing Kwong & Kerrie, 1992 as cited by Heron, 1998).

Heron (1998) suggests that while, practically, this group may be available to care due to retirement, they also represent a significant factor to be considered during the planning of service provision, because they:

- may require help themselves;
- may suffer from a declining ability to care; and
- may have difficulty requesting or accepting help both for the cared for person and themselves.

Situations involving older carers and indeed all carers require forward planning and the development of mutually acceptable solutions, which can be activated in the event of a crisis or significant life event.

Age itself can also influence expectations both of the carer and agencies working with them, for example, some (but not all) older carers *may* not expect to go out socially as frequently as younger people, a view that can be reinforced or not by providers' expectations and judgements (Twigg & Atkin, 1993). This reinforces the importance of services being tailored to individual need in an anti-discriminatory manner.

Gender

The issue of how much carer gender effects caring and levels of service provision has been well explored in the literature. In 1995, of the 5.7 million carers in the UK, 2.4 million were men and 3.3 million were women (GHS, 1995). With respect to gender and race, some small-scale studies of ethnic minority carers have also found the majority of carers (75%) to be women (Wing Kwong & Kerrie, 1992 as cited by Heron, 1998).

Therefore, more women than men were found to be carers and women are also more likely to provide care. However, the link between gender and caring is more complex than solely a relationship between societal expectations and gender obligation. Research on carers over 60 has shown that age itself can have an equalising effect on gender distribution of carers, for example, Fisher (1994) found that the area of spousal care was one area where almost as many men were carers as women as older people were the first most likely carer for their spouses. Spousal carers of Afro-Caribbean elders were also found to be as likely to be men as women, according to Squires (1991) (as cited by Heron, 1998).

With respect to whether service provision is influenced by gender, one study by Graham (1993), found that female carers were less likely to receive practical services. However, another study by Parker & Lawton (1994) suggested that this was found to be true only where the provision of domestic help was concerned. Twigg & Atkin (1994) also found gender differentials in the allocation of the home help service, with services withheld when a female relative lived nearby. However, again the relationship is not a straightforward one as other studies have proposed that when the levels of disability and the presence of co-residency are taken into account, there is no difference between level of service provision between female and male carers (Arber & Gilbert, 1989). Therefore, levels of disability and the presence of co-residency may have an equalising effect on gender differentials in service provision.

Race and Diversity

A very limited amount of research exists in relation to carers from any ethnic minorities. Within Northern Ireland particularly, little is known about the specific experience of care giving amongst the ethnic minority groups represented here. Studies, which have been conducted in the United Kingdom, have been based on small samples of subjects, because of the difficulty in identifying and accessing carers generally and from ethnic minority groups specifically. This is compounded by the fact that accessing people from ethnic minority groups is difficult per se. One local example of this is that estimates suggest that the Chinese population consists of between 8-10,000 people in Northern Ireland and that almost 5,000 people² from other ethnic minority groups also live in Northern Ireland (Holder, 2003). However, the 2001 Census in Northern Ireland found only 4,200 Chinese people in Northern Ireland. The difference in these figures may be explained by research in Craigavon and Banbridge, which found that only one out of twenty people from ethnic minority groups interviewed, had completed the Census (Donaghy, 2004).

2 This figure is comprised of 1700 Travellers, 1600 Indians, 700 Pakistanis, 450 Bangladeshis, 360 Jews and 100 Albanians.

It has been suggested that the low response rate amongst these groups of people may be due to a variety of reasons:

- people did not understand the form or its importance;
- many could not read English;
- forms were collected between 5-9pm when many Chinese people were at work;
- forms were too complex; and
- many asylum seekers and illegal immigrants were fearful about completing it (Donaghy, 2004).

Existing research has suggested that carers from all ethnic minorities are likely to experience commonality with other carers regarding both the characteristics and the consequences of caring, for example, Sharkey (2000) suggests that in most situations the immediate family provides informal care, the primary responsibility of which falls to one family member, usually a woman. In this respect “Asian and Afro-Caribbean families are no different from white families” (Atkin & Rowlings, 1996, p78). Similarly amongst Irish Travellers, women tend to be the main carer for the family and provide a link between those in need and health professionals (National Travellers Women’s Forum, 2002).

With respect to the impact of caring on carers, there are also similarities of experience between Asian and Afro-Caribbean carers and white carers, as “the physical, emotional and financial consequences of care giving [affect] all carers, irrespective of ethnic origin” (Atkin & Rowlings, 1996, p85). Furthermore, the presence of cultural stereotyping serves to “ignore both the diversity of perspectives and behaviour within an ethnic group and the similarities across ethnic groups” (Ahmad, 1996, p51).

It is clear that where carers from all ethnic minorities are likely to have additional difficulty is in accessing support and services. This is due to the obstacles ethnic minority groups face generally in accessing and using services such as communication and language difficulties, cultural differences, racism and inappropriate service provision.

Communication difficulties can be a barrier to accessing service provision, as adult members of ethnic minority groups may not be able to speak or read English, for example, 70% of first generation Chinese cannot speak or read English (Wing Kwong & Kerrie, 1992 as cited by Heron, 1998). A higher figure of 83% has been found in Northern Ireland (Holder, 2003). Connolly (2002) also identified language as a principal barrier within Northern Ireland and raised concern about attempts to use children as interpreters, a practice felt to be inappropriate and likely to cause embarrassment by ethnic minority groups themselves (Donaghy, 2004 and Holder, 2003).

Lack of familiarity with culture and routes to access information can also impact on people's ability to gain knowledge about services available and their uptake of those. They may be adversely influenced by strong norms of self-reliance and help; and they may not be able to relate to the term carer, as they may not have the cultural or linguistic equivalent (Heron, 1995). In the case of Irish Travellers, their lifestyle is based on norms of self-sufficiency and the importance of the extended family, which can affect how comfortable they are in receiving services (www.southglos.gov.uk). People from ethnic minority groups may work long and unsociable hours, making it difficult to find places open to inquire about services. Additionally, low levels of literacy may also contribute to Irish Travellers not receiving sufficient information about accessing available services (Donaghy, 2004).

Discriminatory responses and racial stereotyping from organisations can effect peoples opportunity to avail of or be offered services. This manifests itself through incorrect assumptions being made about their culture by people with limited understanding of it, for example, a common assumption made about Asian carers is that they receive support from extended family and wider cultural community and therefore, they do not require services (Heron, 1995). In fact the processes of immigration and geographical mobility may themselves have impacted on the nature of the extended family, making extended family support more difficult (SSI, 1998).

Lack of cultural sensitivity amongst available services with regards to dietary requirements, religious observance and cultural expectations can render services inappropriate. A recent study in Scotland found that black carers experienced a lack of information and a lack of suitable respite services and interpreting services (Neto *et al*, 2001). In Northern Ireland, people from ethnic minority groups also unanimously felt that services were not appropriate for them, as they were not sensitive to their cultural or religious needs, especially during hospitalisation (Donaghy, 2004). Furthermore, Irish Traveller women within Northern Ireland stated they were uncomfortable when dealing with male social workers and doctors or those unfamiliar with their culture (Dunn & Morgan 2001).

Duration of Caring

The duration of caring can continue for long periods of time with 24% of carers in Great Britain caring for 10 years, 20% of carers were caring for more than 10 years and 23% were caring for between 5-9 years (GHS, 1995). Black carers were found to undertake the same range of caring tasks as white carers and for similar durations. Currently, no information exists regarding the nature (types or levels of care) provided by carers in Northern Ireland nor the duration of this care as determined by number of years spent caring.

Poverty

The experience of being a carer can dramatically impact on household incomes. Eighteen percent of households in poverty in Northern Ireland were found to be caring for an adult either

within or outside of that household (Hillyard *et al*, 2003). Most carers living alone with the cared for person had very low incomes due to the fact that they had relinquished their jobs to provide care and become reliant upon social security benefits which were linked to cared for person's benefits rather than to the carer's needs. In the longer term, most carers were considered to have lost so much financially that they faced poverty in their old age (Glendinning, 1992).

Social Class

As socio-economic class is an important determinant in the likelihood of illness and disability, it is appropriate to suggest that class may have a bearing on the chances of becoming a carer and the experiences of informal carers. Carers from middle class backgrounds are more likely to have more financial and material resources at their disposal, which may enable them to purchase care (Parker, 1990). Furthermore, carers with manual jobs have been found to be more at risk of having to resign from these jobs to undertake caring (Baldwin, 1985). It has been suggested that social class also influences access to services and the response of service providers, as middle class people often have an increased awareness of provision and greater skills in articulation both of which serve to ensure they are more visible and persuasive in negotiating services (Robinson & Stalker, 1992, Rojek *et al*, 1988 and Ungerson, 1987).

Policy/Legislative Basis – tensions in policy

The Griffiths Report in 1988 acknowledged that the state only contributed “a small part of the total care provided to people in need” (1988, p5) and therefore highlighted as one of its main recommendations that service providers should make practical support for carers a high priority, to ensure community care became a reality. Critics of this report accused it of not considering the impact of caring on the carer (Baldwin & Parker, 1989) and of assumptions that an available army of carers was willing and able to care for those who needed it (Twigg & Atkins, 1995).

Many of the original recommendations of the Griffiths Report were introduced in Northern Ireland through People First in 1990. This defined community care as health and social care provided outside of hospitals and reinforced the importance of the role of informal carers in supporting community care policy, thus, “the family ... continues to be the major supplier of social and personal care, and the obligations of kin and affection will remain powerful motivators. It is in society's interests to sustain that motivation and to see that appropriate packages of support are assembled for people who are able and willing to care for others” (1990, p11). It outlined the following key principles, which should underpin the development of community care:

- services should respond flexibly and sensitively to the needs of people and those who care for them;
- services should intervene no more than necessary to foster independence; and

- services should be targeted to those in greatest need.

While People First advocated that family, friends and neighbours could all contribute to caring, the reality appeared to be that the family would play the major role in caring for family members. There was an inherent tension in this policy, with its requirement to target services while intervening no more than necessary, at the same time as emphasising the need for the provision of adequate and flexible services to support users and their carers.

The Report of the Dementia Policy Scrutiny (1994) acknowledged the particular needs of carers of people with dementia in Northern Ireland. It recommended that carers were given access to information, advice, counselling, appropriate training and services at an early stage and that their needs and abilities be taken into account when assessments were being conducted. These were to become recurrent themes in social policy, with carers' rights to assessment soon reflected in governmental policy and legislation.

A significant piece of legislation, enacted in England and Wales, and which specifically focused on carers and their ability to provide care, was the Carers Recognition & Services Act (1995). This Act allowed for the assessment of the carer's ability to provide or continue to provide care and represented an important step in recognising carers' needs and contribution. In its attempts to define carers within the legislation, it suggested that carers constituted those providing "a substantial amount of care on a regular basis". However, while it gave carers a legal entitlement to an assessment, there was no obligation to provide services to carers and it failed to establish legislatively what was considered "substantial" or "regular". While it was never legally extended to Northern Ireland, Health and Social Services Boards and Trusts were advised to adopt its principles. However, this meant that while carers in Northern Ireland could request an assessment, they did not have a legal right to assessment as carers did in the rest of the United Kingdom. Research by Carers Northern Ireland and Carers United Kingdom in 1997, found that where carers had their needs assessed they were more likely to receive increased service provision. However, in this study only 495 out of 1655 carers surveyed knew they had a right to an assessment in the first place (Carers National Association, 1997). Thus the impact of the legislation was somewhat limited.

The Royal Commission on Long term Care (1997) delivered its report in 1999 and again carers' issues were highlighted nationally. This time the emphasis was on the provision of support services to carers rather than assessment. It issued two carer specific recommendations – better services should be offered to carers and that government should consider a national carer support package. One of the ramifications of this report was the development of carers' strategies throughout the United Kingdom.

In England, The National Service Framework for Older People established seven standards for working with older people in 2001. One of these, which related specifically to carers, was

standard 7, person-centred care. This standard advocated achieving person-centred by listening to what users and carers identified as important in service provision and needs assessment. While not fully operational in Northern Ireland, its principles have been adopted by Boards and Trusts. Initial examination of its impact in England, has suggested that this has led to increased carer services, employment of carers' support workers and carers' centres (www.dh.gov.uk dated 25/3/04).

Almost 10 years following the implementation of the community care reforms in Northern Ireland a review of the community care system was published in April 2002. Its terms of reference were to identify barriers to the delivery of good community care services, identify good practice and to make recommendations for improvement. The review was based upon consultation with a range of relevant agencies and the general public. In relation to carers, it highlighted 3 main things – that many older people were concerned about their carers (they felt they required more help), an increasing number of carers were themselves older and frail and both users and carers were anxious that a crisis would precipitate care home admission.

The Community Care Review 2002 made a number of recommendations, some of which were carer-specific. It advocated that carers needs should always be considered in service provision and planning, particularly the needs of the growing number of older carers. In response to this in the short term, it recommended that current services be maintained and developed regarding access at short notice and at times of stress and illness, increased provision of planned breaks and the development of support groups. In the longer term, a carers' strategy should be implemented to ensure a range of practical support for carers, establish models of good practice and develop a set of key principles for carer support.

In October 2002, following national strategies for carers in England, Scotland and Wales, Valuing Carers (2002), proposed a carers' strategy for Northern Ireland. The rationale of Valuing Carers (2002) was "to identify the needs of carers; to identify any unmet need; to gather information about policies, practices and services that affect carers and to set out an integrated strategy for future action" (p.3). It established 5 principles to underpin work with carers:

- "carers should be treated as real and equal partners in the provision of care;
- carers need flexible and responsive support;
- carers have a right to a life outside of caring;
- caring should be freely chosen; and
- government should invest in carers" (p11).

Valuing Carers (2002) set out 19 recommendations related to areas of information and training, support services, employment and help for young carers. Carers were fully involved in the development of these key principles and in subsequent working groups, which were established to implement the strategy's recommendations. The work of these groups is ongoing.

Some of the difficulties identified within previous legislation were addressed with the introduction of the Carers & Direct Payments Act (Northern Ireland) (2002), which was implemented in Northern Ireland on 31 March 2003. It gave carers a statutory right to separate and independent assessment and placed a statutory duty on Health and Social Services Trusts to inform carers of this right. It also allowed Health and Social Services Trusts to provide services directly to carers, based on their identified needs, as distinct from the cared for person. These services included vouchers for carers' breaks (not yet implemented) and it extended direct payments to carers' aged 16 and over, parents of disabled children and 16-17 year old service users. Furthermore, it stipulated that the Children (Northern Ireland) Order (1995) be amended to ensure that young carers were considered "children in need".

This was to be welcomed for a number of reasons. It established a legal right to assessment for carers in Northern Ireland, regardless of the choices made by the cared for person concerning either assessment or service provision. It also radically moved the focus of responses to caring beyond passive recognition to active provision of support services. For young carers it also specifically served to recognise the hidden contribution made by young people to caring. The possible provision of vouchers and direct payments may significantly increase the potential for flexibility and choice regarding the timing of services delivered to carers to meet their needs, although all sections of the legislation need to be implemented for its full impact to be felt.

Regionally, the impact of this legislation has yet to be fully explored. However, the Carers and Disabled Children Act (2000) in England has been enacted for almost 4 years, and research has suggested a limited effect to date. Carers UK in 2003 found that only 32% of carers were receiving an assessment compared with 21% in 1997, and only 37% of those carers assessed had experienced an increase in service provision as a consequence.

What Carers Value?

A substantial body of research exists which describes what carers need and how they would prefer services to respond to those needs.

The two general and over riding principles reported, that is flexibility and sensitivity, should influence how specific services are delivered. Lack of flexibility has been one of the main criticisms levelled at respite care, which has been described as "rigid and predetermined" (Cuthbert, 1996, p40). However, it can be difficult for service providers to balance the necessary flexibility with the practical management of a service. For services like respite to be more flexible there would have to be radical changes in current service provision and availability.

Sensitivity is required at all times in work with service users and carers but specifically regarding the role and needs of a carer when someone is entering residential care or being

admitted to hospital. Carers may need reassurance and deserve to be fully consulted and involved in their relative's care particularly when those services are attempting to assume the entire caring role for an individual.

In terms of carers needs, a number of researchers have identified these with surprisingly consistency (Richardson, 1989, Heron, 1998). The National Carers Association produced a fairly comprehensive plan of what carers need based upon work by Richardson in 1989:

- recognition of their contribution and of their own needs as individuals in their own right;
- services tailored to their individual circumstances, needs and views;
- services which reflect an awareness of differing racial, cultural and religious backgrounds;
- opportunities for a break, to relax and have time to themselves;
- someone to talk to about his or her own emotional needs;
- information about available benefits and services;
- an income which covers the cost of caring;
- opportunities to explore alternatives to family care; and
- services designed through consultation with carers, at all levels of policy and planning.

Heron, 1998 developed some of these specifically to provide more detail regarding what carers need:

- a break and practical support, for example, respite care and help with personal care;
- information, especially regarding benefits and services;
- training in caring skills, for example, lifting and handling techniques, rehabilitation skills, and strategies for dealing with difficult behaviour, anger and aggression;
- emotional support to allow them to share problems and talk about caring, for example, individual counselling, support groups and telephone support. Research by McKee *et al* (1999) found that the carer's willingness to continue to provide care was a major factor in determining admission to care for individuals. Warburton (1989) also found that the breakdown in the caring relationship is more crucial than level of disability in precipitating admission to residential care;
- improved communication and problem solving skills. Lack of communication between carers and cared for person may be a hidden problem based on previous ways of relating. These could be enhanced through assertiveness training, communication skills training and problem-solving techniques;
- stress management, that is, how to understand it and reduce it; and

- involvement in planning and delivery of services to ensure services are organised in ways which best meet their needs.

In spite of the existence of this information, which could be considered guidelines for professionals engaged in care planning and provision for a considerable period of time, carers still “continue to report a wide variety of unmet needs and lack of formal involvement in decision-making” according to research by Pickard & Glendinning, (2002, p150).

Complexity of Caring

The nature of caring is further complicated by the fact that one carer may care for more than one person, for example, 18% of carers in the General Household Survey (1995) were caring for more than one dependent (Rowlands, 1998). Indeed, in Northern Ireland, 43% of carers who were caring for elderly parents or in-laws were also caring for dependent children (NIHPS, 2001).

The perception that multiple carers share caring is not a concept borne out by research as a significant percentage of carers are in fact sole carers – 65% of the 5.7 million carers in Great Britain (GHS, 1995). Twigg and Atkin (1995) also found shared care to be rare. Whilst the care of an individual *may* be shared, often one person assumes the role of principal or main carer and their experience of the caring role will be affected by the existing nature of family relationships. In the absence of supportive relationships within the family, the isolation and stress experienced by the carer can be exacerbated (Heron, 1998).

The problematic issue of identifying the main carer in any one situation has been offered as a barrier to assessment and service delivery. However, the literature provides a guide to assist in identifying who has the potential to become the main carer. Whilst caution should be applied in using the guide oppressively with families without clarifying their reality, nevertheless it serves to inform potentiality for adopting a caring role and therefore is of use in the identification of main carers.

Finch (1989) established a hierarchy of caring obligations where marriage/partnership, co-residency, parenthood/childhood and gender all increased the likelihood of someone becoming a carer:

- in the first instance, the presence of a marital/partnership relationship means that spouses/partners are the first most likely carer. In fact this is an area where almost as many men as women are carers (Fisher, 1994);
- the second most likely “obligation” is based on co-residency, with those sharing the same household as the cared for person the next most likely to provide care. Parker and Lawton (1990) identified 1.7 million carers as sharing the same household;

- in the absence of these first two factors, the presence of a parent-child relationship is the next determinant in who assumes the caring role. Parker (1992) found that one third of all young carers were caring for a parent; and
- ultimately, gender may be the crucial factor in who provides care, especially where a choice exists between male and female relatives. Research by Aldridge and Becker (1994), found evidence to suggest a delegation of personal care tasks from fathers to their daughters.

Perceptions of Family Involvement in Caring and the Impact on Service Provision

The provision of services to carers is an important facet in supporting carers in their continuation of informal care. However, “care giving is a relationship between two people, and it has all the complexities of intimate human relationships. Any discussion [of caring] must take this into account” (Braithwaite, 1990, p53-4). Therefore, a number of factors such as the influence of other family members, the relationship between the carer and other family members, differing perceptions of family involvement and the values and language employed by providers of care, may all mitigate against seeking, offering and accepting services from social service providers.

Influence of family members can operate in two main ways. Firstly, they may influence a carer’s response to a particular service and affect whether or not they actually accept it. Family have been found to make judgements on services and influenced the carer’s decisions in accepting them which in turn influenced carers’ decisions about services (Twigg & Atkins, 1995). Therefore, family may have a positive role in giving permission and encouraging carers seeking assistance. Secondly, they may be direct contributors to care. However, such input is frequently quite limited and restricted to provision of transport or shopping; rarely is personal care provided (Twigg & Atkins, 1995).

Research has suggested that statutory agency service providers had direct contact with the wider family infrequently, but made assumptions about them which could sometimes affect the level of services provided by them or indeed if any were offered at all (Twigg & Atkins, 1995). Statutory agencies had a different perception of how formal services would complement informal ones and of how substitution of care should occur within families. Therefore, statutory agency staff were found to make assumptions about what the wider family could provide, sometimes without explicitly clarifying this. This resulted, in some instances, in no help being provided by statutory agencies to the carer at all (Twigg & Atkins, 1995).

The relationship between the carer and other family members can create a precedent whereby carers do not want to ask family for help as they consider other family members to have their own lives to live. Thus, carers themselves may impose limits on the types and levels of help

they will accept from family members. They may not want to approach family for help in the first instance, preferring assistance from formal services. The implication is therefore that assumptions made by statutory agencies about how wider family could complement service provision may not reflect the perspective held by the carer regarding family involvement.

Furthermore, in describing carers, service providers sometimes made moral distinctions between those deserving and undeserving of help and of what it was deemed appropriate to request. Carers were perceived as “virtuous” or otherwise, based on value judgments by statutory agencies (Twigg & Atkin, 1995). These judgments could to some degree, be explained by the tensions in implementing a policy which advocated the support of carers at the same time as targeting services to those in greatest need. This invariably led to statutory agencies attempting to manage these tensions, however there were insufficient financial resources to always meet the needs of carers.

Factors impacting on Uptake of Services

It has also been suggested that how carers perceived the caring role and how service providers work with them in offering services can impact on the uptake of services. Twigg & Atkin (1995) found that carers adopted 3 basic responses to their caring role. These were:

- *Engulfment* – Carers who were “engulfed” by their caring role often found it difficult to request or accept help especially if help was directed at them rather than the cared for person. Many carers in this category could not or did not work and so did not consider themselves to qualify for assistance. Others were so engulfed by the demands of caring that they had no surplus energy to pursue help. As a consequence, they often remained invisible to service providers. The “engulfed” response was more often associated with females than male carers and with spousal carers (Twigg & Atkin, 1995);
- *Balancing/boundary setting* – Carers who adopted this response were able to detach themselves from the caring situation and maintain a greater separation between the cared for person and themselves. In essence they were able to “balance” their caring by setting clear boundaries to their role and responsibilities. Many carers in this group identified themselves as carers, considering their caring responsibilities as a type of job, which helped them manage it and maintain some life balance. This impacted on what carers felt it was appropriate to ask for and accept. Thus, carers in this category requested and accepted more help as receiving help was considered appropriate and not regarded as a personal failing. Indeed, service provision was viewed as useful and a legitimate support to caring. This employment orientation was found to be more common amongst male carers (Ungerson, 1987); and

- *Symbiosis* – In this instance, carers felt that they benefited in a positive way from their caring role and therefore did not wish to relinquish their responsibilities. However, carers were content to accept services as long as they did not overly impinge on their role as a carer. This response was found to be less characteristic of carers of older people and care giving where the physical demands were considerable (Twigg & Atkin, 1995).

Therefore, the existence of a range of adaptive responses would suggest that providing services to carers is far from straightforward and uniform in nature and highlights the need for individualised, sensitive assessment and service provision.

Statutory agency relationships with carers are often typified by ambiguity and the application of different models of how they work together. Twigg (1989 and 1992) devised 4 models to describe the fluid relationship between agencies and carers. She suggested carers could be perceived as:

- resources – where cared for person is the primary focus;
- co-workers – morale and well-being of carer is recognised;
- co-clients – carer considered in need of service themselves with the main focus of involvement being the carer; or
- superseded carers – carer and cared for person both viewed as separate entities, with independence for both seen as having an equal focus.

Frequently, statutory agencies shifted between one perception and another with little consistency in terms of the model employed in the planning, delivering and reviewing services. (Twigg 1992). The implication of this ambiguity is that opportunities may be lost to fully explore and recognise carers and develop a consistent approach to work in supporting them.

International perspectives

The international picture of caring is especially interesting regarding the progress made in Europe and Australasia in relation to both perspectives of caring and the pace with which government social policy has developed. Similar concerns are being raised throughout Europe about the continuing availability of families to provide care with a rising number of older people and falling birth rates. A survey in 1993 found that high proportions of older people felt that family were less willing to care when compared to the past, for example, 80% of people in Portugal and Spain, 70% in Greece and Italy, 61% in Germany, 59% in Denmark and 58% in the United Kingdom (Means & Smith, 1998).

Differing perceptions of the role of the family in providing care are held with Greece and Germany placing a legal obligation on families to provide care. European perspectives on the amount of support expected from families also varied from “systems where the family

provided virtually all the support, to those where family care was an optional extra to state services” (Means & Smith, 1998, p 201). For example, Portugal and Spain were two countries where support services were generally inadequate and there was a greater dependence on the family, particularly female carers.

In social policy terms, most European countries still rely fairly exclusively on family for care rather than providing services to them. Few examples exist of European countries where any real and formal practical supports have been provided to carers, especially not for carers in their own right. For example, in Germany, all support to carers is dependent on the older person’s entitlement to social insurance. While cash benefits are available, carers have no entitlements in their own right to either benefits or services (Glendinning, 2003). In most countries there is little recognition of carers, their experiences and needs, or of services to support carers in order to continue to care.

A lack of uniformity exists in the levels of practical provision made for carers throughout Europe with services provided in an ad hoc manner and reliant on voluntary sector rather than the statutory sector provision. Generally, outside of the United Kingdom, policies to support carers “remain fragmented and weak” (Glendinning, 2003, p28) and there are few policies which give carers a statutory entitlement to assessment.

In terms of financial support, few European countries are operating policies in advance of the United Kingdom, in fact many are behind the United Kingdom. In the Netherlands, for example, no system operates for the making of cash benefits to carers (Glendinning, 2003). In a survey of sixteen countries, Denmark was the only country with a system, for the making of care payments specifically for caring to carers, similar to that of the United Kingdom (Millar & Warman, 1996). Cash benefits are available in Sweden, where family members can be paid as care givers provided a high level of care and attention is needed. However, in most areas, these care givers have worse terms and conditions than those employed as home helps or nursing assistants.

The situation regarding recognition of carers has progressed in Australia where Carers Australia has been active in promoting the recognition and support of informal carers. In 2003, the Queensland government established a Carer Recognition Policy which set out its philosophy and guiding principles in relation to carers. These principles were to:

- acknowledge, respect and support carers’ contributions;
- accept their significance;
- ensure information provided on their rights;
- acknowledge carers as individuals;

- value their skills and expertise;
- acknowledge and identify diversity;
- ensure programs and services are responsive and flexible; and
- ensure sharing of information and decisions on matters effecting them. (<http://www.disability.qld.gov.au> at 22/3/04).

The Federal Budget for 2003 also stipulated that \$80 million would be provided over four years for additional support in the form of respite care services, specialised equipment, transport, counselling services, and education and training. However, even within Australia, while recognition of carers is being advanced, carers still have no independent entitlement to assessments or services (Glendinning, 2003).

Carers Australia (2003) have acknowledged governmental support, but also highlighted the need for the Australian government to support carers by:

- increasing the carers' allowance;
- encouraging more flexible working practices to enable carers to remain or return to paid employment; and
- developing carer support in terms of training for carers and the building of carer networks. (<http://www.carers.asn.au/policy>).

However, while some progress is evident, there appears to be a lack of focus on services being provided in relation to specific identified carer needs or on the development of carer specific service provision.

Thus, it can be seen that there would be more resonance between the development of social policy in Australia and the United Kingdom, than in other parts of Europe. However, the United Kingdom can be considered to be more advanced when compared with other parts of Europe and Australia as “the entitlement of carers in the United Kingdom to an assessment of their own needs, independent of the needs of the older person receiving care, is unique in this respect” (Glendinning, 2003, p29). Furthermore, the United Kingdom has not only begun the process of providing services directly to carers but also of involving carers in the actual planning and delivery of those services and in the wider strategic planning and review of services generally.

Conclusions

The development of professional practice both in assessing carers' needs and in providing appropriate services to meet those needs represents a significant challenge.

Research has focused on specific areas of care giving, but has been limited, regarding the duration and types of care provided within Northern Ireland and the extent to which ethnic

minority groups are able to access services. Additionally, little is known regarding assessment practice and how best to involve carers in the planning and delivery of services. Finally, there is insufficient clarity regarding what constitutes support services for carers as opposed to services for the cared for person and the extent to which agencies are responding appropriately to carers' needs.

However, progress has been made in carers' rights compared with other European countries and Australia. Few examples exist of European countries where any formal practical supports have been provided to carers, especially not to carers in their own right, nor where carers are entitled to independent assessments of their ability to maintain the caring role. Often, even where support is available, it is dependent on the cared for persons entitlement to social insurance and while cash benefits may be available, carers have no entitlements to these in their own right.

In the United Kingdom, the political will exists to advance service provision for carers and to further involve them in the planning of such services. Much is to be gained if a way can be found to develop a systematic approach to work with carers, perhaps through the development of guiding principles which uphold the carer's sense of pride in their role, empower them to see their caring role as a separate function rather than merely an extension of obligation and to enable them to accept services which support them in continuing to care.

Statutory agencies continue to strive to find mechanisms for identifying carers. General Practitioners are often considered by carers as best placed to understand and identify them. The London Borough of Tower Hamlets has therefore introduced an innovative system whereby carers are encouraged to register as a carer with their GP, whereupon they qualify for a discount card scheme and are encouraged to have a carer assessment.

To build upon and sustain the progress already made in working with carers, professionals need to receive additional training to continue to identify and respond to carers in an individual, empowering, skilled and sensitive manner.

An examination of progress regarding carers' assessments, the extent to which social care services meet the needs of carers and best practice in carer involvement are essential prerequisites for the systematic planning of future work in this area.

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