

SECTION 9

**DEPENDANT STATUS,
EQUALITY & HUMAN RIGHTS:**

**ACCESS TO HEALTH AND SOCIAL
SERVICES IN
NORTHERN IRELAND**

**Literature Review-
Equality & Human
Rights: Access to Health
and Social Services in
Northern Ireland**

Dependant Status, Equality and Human Rights: Access to Health and Social Services in Northern Ireland

All public authorities in Northern Ireland have a statutory duty, under Section 75 of the Northern Ireland Act, to have due regard to the need to promote equality of opportunity between persons with dependants and persons without. Persons with dependants can be defined, for example, as those with personal responsibility for the care of a child, the care of a person with an incapacitating disability and/or the care of a dependent older person⁸⁸. The care and support provided by carers is often unpaid and informal. It is important to bear in mind that carers and those with dependants are not always non-disabled adults and that carers can themselves be young people, older people and people with disabilities.

Similar to the first literature review conducted in 2001⁸⁹, little specific research was uncovered during the current literature which implies that persons *without* dependants are denied access to health and social services because of their non-dependant status⁹⁰. There is, however, evidence to suggest that persons *with* dependants experience a range of barriers in accessing and utilising health and social care. This section will therefore primarily focus upon the needs and experiences of carers in accessing health and social services.

The section begins by exploring five main access barriers to health and social care which have been identified in a recent comprehensive literature review conducted by Arksey et al (2003). In recognising that carers are not an homogenous group, the section will briefly explore the access difficulties experienced by diverse range of carers such as young carers, older carers and carers from black and minority ethnic communities.

In the process of conducting the literature review it became evident that carers also have diverse needs and experiences according to the different characteristics, or the nature and extent of the

⁸⁸ Equality Commission for Northern Ireland (2004) Section 75 of the Northern Ireland Act – Practical Guidance on Equality Impact Assessment.

⁸⁹ Bunting (2001)

⁹⁰ However, it is suggested that many childless people feel ostracised and marginalised by Government policy which places a premium on “the family” and which gears services around family-friendly policies. (BBC News Online, “Does Society Discriminate Against the Childless?”, 18th August 2000).

disability, of the person they provide care for. Carers with children and adults with profound and multiple disabilities, carers of people with mental health problems, and foster carers and kinship carers are therefore briefly explored to illustrate this point.

This section then concludes by reviewing the human rights of carers within a health and social care context and argues that this issue merits much greater attention than it currently receives. However, it must again be stressed that this section *does not* provide a definitive discussion of all the human rights and equality issues relevant to carers.

Carers' Access to Health and Social Services

There has been a policy drive in recent years towards supporting carers in their caring role and ensuring that health and social services assist carers in maintaining their own health and well-being. Yet, despite this many carers continue to feel marginalised and often believe that their own particular health and social care needs are overlooked (Arksey et al, 2003:1).

Five main barriers impeding carers' access and utilisation of health and social care services have been identified by Arksey et al (2003) in what is perhaps one of the most comprehensive literature reviews of the difficulties experienced by carers in accessing health and social care. These barriers, which are briefly outlined below, relate to professional characteristics, service issues, language or cultural issues, care or care recipient characteristics, and information and knowledge issues.

Typology of Barriers to Access of Health Care for Carers (Arksey et al, 2003):

1. **Professional Characteristics Barriers:** includes a lack of recognition amongst some professionals of the carer's role; a lack of awareness amongst some professionals of the needs of carers; professional uncertainty about roles and boundaries; reactive rather than proactive approaches; prioritising the needs of the care recipient to the detriment of the carer; and, conceptualisations or stereotypes of carers which are not conducive to meeting their needs (2003:40-44).

2. **Barriers relating to service issues:** key features obstructing carers' access to health care include, GP surgeries not identifying or carers' health records; a lack of training in carers' issues amongst staff; "gate-keeping", inflexible appointments systems; waiting times; and, lack and/or cost of transport and parking at health care facilities (2003:45).
3. **Barriers relating to language or cultural issues:** key problems identified include, the difficulties experienced by carers whose first language is not English; inadequacies in translation and interpreting services; racial prejudice and stereotyping; professionals lack of knowledge about cultural or religious practices (2003:50).
4. **Barriers relating to carer or care recipient characteristics:** beliefs and behaviours of carers and/or carer recipients which inhibit access to health and social care include, the carers' approach to health promotion; carers' and carergivers' help-seeking behaviour; personal or cultural beliefs and practices; and the care recipients' attitude. The literature review highlights that many carers often do not define themselves as such and do not therefore see the need to access services. Other carers felt that they were not assertive enough to obtain the services they required (2003:54-58).
5. **Barriers relating to information and knowledge issues:** problems identified include, carers not being provided with sufficient information regarding available services and how to access them; professional concerns about confidentiality and disclosing information to carers (2003:58).

Arksey et al (2003:63) provide a wide range of recommendations aimed at addressing the service accessibility barriers experienced by carers. A number of these recommendations are outlined overleaf. It is strongly suggested that the DHSSPS and associated bodies take these recommendations and the issues identified by the Arksey et al (2003) report into careful consideration.

Recommendations: Carers' Access to Health and Social Services

(Arksey et al, 2003)

Professional Characteristics Barriers:

- **Pre and post registration training for all health and social care professionals and frontline staff to ensure that they identify and accept carers as a discrete group with their own particular health needs.**
- **Adoption of care sensitive practices as an integral part of routine care.**
- **Incentives for primary care professionals to focus on carers' health and proactively offer health checks for carers.**

Barriers Relating to Service Issues:

- **Identifying and "tagging" of carers in medical records including hospital admission and discharge notes.**
- **Inclusion of a carer questionnaire at new patient registration, over 75s health check and other standard health screening appointments.**
- **Provision of health care services in settings which are accessible and acceptable to carers.**
- **Identification of a point of contact or carer support worker in each GP practice or health centre.**
- **Lowering the threshold of access to services to permit earlier and preventative work with carers.**
- **Greater recognition of the needs and special circumstances of carers in the way in which appointments and electoral procedures are arranged.**
- **Greater flexibility and availability of respite care services.**
- **Recognising and addressing the transport needs of carers (especially those in rural areas), this could include an increased use of home visits.**

Barriers Relating to Language and Cultural Issues:

- **Assistance with reading, writing and form completion.**
- **Expansion of professional interpreting and translation services.**
- **Cultural diversity training for staff.**

Barriers Relating to Carer or Care Recipient Characteristics:

- Education for carers by health and social care professionals and/or carer support workers regarding the benefits of health promotion behaviours and regular screening.
- Promotion of positive images of carers and disability, for example, through health and social education programmes and citizenship programmes.

Barriers Relating to Information and Knowledge Issues:

- Introduction of initiatives and procedures designed to overcome professionals' concerns about medical confidentiality issues.
- Provision of information regarding service availability in a variety of languages and media.
- Providing health and social care professionals with access to up-to-date information on national and local services for carers.

Gaps in Research

The Arksey et al (2003:11-12) literature review further suggests that there are many areas in which there is insufficient knowledge about carers' access to health and social services. For example, little is known about carers' access to hospital-based services, tertiary services, screening programmes, dental services and optical care. In addition to this, the review highlights that little is known about different groups of carers such as young carers, older carers, carers from black and minority ethnic groups, refugee and asylum seekers who are carers, and carers of people with stigmatising conditions (for example, HIV, AIDS, mental health problems, drug and alcohol misuse problems).

The review identifies current gaps in research and makes a number of recommendations for the commissioning of research in a number of areas which the DHSSPS and its associated bodies may wish to take into consideration. These areas are outlined overleaf for consideration.

Recommendations: Research (Arksey et al, 2003)

The review recommends further research into:

- **Carers' access to services in their own right. Carers access to services must not be confused with those of the care recipient.**
- **Carers' access to health care in different settings other than primary care (for example, secondary and tertiary care).**
- **Culturally sensitive services, that is, research into what type of culturally sensitive services are needed and how such services could be implemented.**
- **Need for detailed qualitative information about carer's access to information and communication technology including access and use of the Internet (to access services and information). Findings could be used to inform e-health websites for carers.**
- **More research into the needs of specific user groups (for example, young carers, older carers, carers from black and minority ethnic communities, asylum seeker and refugee carers, carers of people with stigmatising conditions such as HIV & AIDS, alcohol and drugs misuse and mental health problems.**

Young Carers

There has been a growing awareness in recent years of the needs and experiences of young carers. The Princess Royal Trust for carers defines a young carer as, *"a child or young person under the age of 18 carrying out significant caring tasks and assuming a level of responsibility for another person, which would normally be*

*taken by an adult*⁹¹. As Thomas et al (2003:36) notes, the issues of defining a “young carer” has often been complex and somewhat controversial and involves determining what is normal interfamilial relationships and when the degree of caring becomes an issue for the state.

It is suggested that the actual number of young carers may be substantially higher than that reported in Census figures. A possible reason for this may be that many parents (who complete the Census form) may not wish to admit that their child is either looking after them or taking on a caring role for a sibling (Princess Royal Trust for Carers Press Release, September 2004). Young carers are notoriously difficult to identify given that many fear losing their friends, being bullied or ridiculed, or being separated from their parents upon disclosure of their caring role (Banks et al, 2002).

Research suggests that the caring role has both negative and positive affects on young people. It is notable that the vast majority of young people actually want to provide care. Other positive impacts of caring include, maturing earlier, developing life-skills and learning to take responsibility (Thomas et al, 2003:37). However, as Thomas et al (2003:36-37) suggests, caring can also have a range of negative impacts including:

- **Physical Impact** – lifting a person who is sick or disabled can lead to an increased likelihood of back problems in adulthood.
- **Social Impact** – decreased opportunities for socialising with peers or for sporting or leisure activities which can lead to social exclusion.
- **Educational Impact** – can affect school attendance and performance, lack of opportunities to participate in out-of-school activities including school visits and holiday programmes. Can impact upon qualification attainment and future career opportunities.
- **Emotional Impact** – can lead to feelings of resentment, anger, emotional exhaustion, isolation, stress and depression.

⁹¹ Extracted from the Princess Royal Trust for Carers website.

Research suggests that young carers are often overlooked in regards to the assessment of the needs of those they are caring for (Banks et al, 2002). One reason for this is that professionals often carry out assessments during the day when the young person is not present. Also, professionals in contact with families often fail to talk to young people about their caring roles and subsequent needs (Banks et al, 2002).

The majority of services tend to focus upon supporting the family member requiring care, however, in recent years there has been an emergence of projects aimed specifically at young carers. These projects are mainly provided by voluntary organisations with some statutory funding (Banks et al, 2002). However, it is suggested that these services are only in contact with a limited number of young carers and that the needs of the vast majority of young carers is still not being adequately addressed. Banks et al (2002) highlight that, while such projects are extremely useful, the difficulty remains that many are typically short term and of limited duration.

Banks et al (2002) acknowledge the importance of these projects and the provision of counselling in schools for young carers. However, they suggest that these are perhaps not the most effective ways of addressing the needs of young carers given that many are reluctant to reveal that they are carers to statutory services. Banks et al (2002) advocate that the use of non-traditional methods of service delivery may be more beneficial. Such as providing counselling and support through Internet and telephone services (particularly for young carers in disadvantaged areas who may not have access to the Internet).

It is important to note that many of the issues in regards to young carers highlighted in this section (that is, recognising the needs of young carers in the assessment process, acknowledging the need for greater co-operation with the education sector, the provision of information services via non-traditional means) have been recognised and included in the recommendations of the DHSSPS "Valuing Carers" paper published in 2002.

Older Carers

The 2001 Household Panel Survey reveals that the majority of carers in Northern Ireland tend to be late middle age or of a

pensionable age. Data from the survey indicates that 54% of carers in Northern Ireland are aged 45 years and over and that just over one in five (21%) are aged 60 years and over (Evasion, 2004:2).

Many factors including advances in medical technology and higher standards of care mean that older people are now living longer. The 2001 Census, for example, demonstrates a large increase in the number of people aged 85 and over. Neno (2004:14) suggests that the increase in the older population and an increase in life expectancy mean that there are an increasing number of older people available to take on the role of carer.

What follows is a brief discussion of the needs, experiences and access barriers experienced by two particular types of older carers, namely older carers of adults with learning disabilities and older spousal/partner carers. Although this does not provide a definitive account of the many diverse needs of different older carers it does at least provide some illustration of the need to recognise that older carers are not a homogenous group.

Older Carers of Adults with Learning Disabilities

Hubert & Hollins (2000) highlight that the majority of people with learning disabilities in the UK live at home with their families (and usually with their mother in later life). The Department of Health (2001) estimate that approximately 25% of people with learning disabilities and their family carers live in the community as “hidden families”. That is, they remain unknown to statutory services until a crisis occurs. It is likely that a high proportion of these “hidden families” are people with learning disabilities living with older family carers (Foundation for People with Learning Disabilities, 2003a).

People with learning disabilities now have a greater life expectancy than ever before and as a result there is an expanding population of older parents who are continuing to care for a son or daughter well into old age. Hubert & Hollins (2000) suggest that often older carers who have adult children with learning disabilities are often reluctant to access services for a number of reasons. For example, some may still fear that accessing services may lead to their child being placed in institutional care. Many would have originally attempted to access services in the 1950s and 60s and

may be unaware of the radical changes and ideological shifts toward institutional care which have taken since then.

Older carers of adults with learning disabilities often have their own health and social care support needs. Ageing carers and their adult children have a complex set of individual and joint needs. It is often the case that as the carer gets older the roles become reversed and the person with the learning disability begins to take on aspects of the caring role (Hubert & Hollins, 2000).

Hubert & Hollins (2002) stress that co-operation between specialist learning disability services, generic older persons services and voluntary services, is essential in cases involving older parents providing care. They further suggest that if the parent should develop dementia in later life there should be no reason to split parent and child and that social services should explore the feasibility of moving both into a facility for older people if both wish to do so. A report by the Foundation for People with Learning Disabilities (2003b:5) further argue that there is a clear need for learning disability services to make stronger links with older people's social and primary health care services in order to provide a joined up approach to supporting older carers.

A number of recommendations for improving older carers' access to health and social care services have been identified by the Foundation for People with Learning Disabilities (2003). Whilst the recommendations are targeted at the Department of Health (GB) they may also be of relevance in a Northern Ireland context. The recommendations are outlined below for consideration.

**Recommendations: Older Carers of People with Learning Disabilities
(Foundation for People with Learning Disabilities, 2003)**

- **Services must work in partnership to identify older carers of people with learning disabilities and develop joint approaches to ensure that needs are met.**
- **Information systems on the number and needs of older carers of people with learning disabilities should be established as a matter of urgency. Mechanisms should be established whereby information collected by different**

agencies is co-ordinated and collated.

- **Older families should be visited at least annually to obtain an up-to-date record of family circumstances.**
- **Arrangements should be put in place to ensure that older carers have accessible, accurate and up-to-date information about services and support options.**
- **Strategies should be put in place to ensure that older carers are consulted in the decisions regarding the planning, development and provision of services.**
- **Older carers should be offered the option of emotional and social support in a safe and confidential setting (for example, on an individual basis or as part of a carers' group).**

Older Spousal/Partner Carers

Many feel that the issue of older spousal/partner care-giving should be given more attention than it has currently received to date (Neno, 2004:14). Thornton (1989) Spousal/partner carers have a tendency not to recognise that they are carers, with many accepting that the role of carer is part of their marital commitment (Neno, 2004:14). This may especially be the case amongst many older men who provide care for a spouse or partner (Gollins, 2001).

Navon & Weinblatt (1996) suggest that the difficulties and needs which are unique to older spousal/partner carers have not been clearly distinguished from those of other carers (Neno, 2004:15). There is clearly a need for further research in this area in order to identify the barriers to accessing health and social services experienced by older people caring for their spouse or partner.

Recommendations: Older Spousal/Partner Carers

- **More research is needed into the barriers experienced by older spousal/partner carers in accessing health and social services.**

Black and Minority Ethnic Carers

Carers from black and minority ethnic (BME) communities often experience a range of obstacles when engaging with health and social services. A recent report by the Welsh Assembly Government⁹² (2004) provides an analysis of these barriers to service access. Although the report focuses upon BME carers in Wales, many of the access barriers identified are likely to be relevant to BME carers in Northern Ireland.

The main barriers identified by the report relate to self-identification, a lack of culturally sensitive services, language barriers, stereotyping and a lack of knowledge:

BME Carers: Barriers to Service Access (Welsh Assembly Government Report, 2003)

- **Self-identification:** often BME carers do not define themselves as such. Many people from BME communities tend to see caring as part of their customary or familial role and as a result are reluctant to access health and social services. There is also a tendency for these carers to only access mainstream services as a last resort, often when situations have reached crisis point.
- **Lack of culturally sensitive services:** BME carers are unlikely to access health and social services which are not culturally sensitive (for example, reluctance to access meals on wheels if they do not provide Halal meat).
- **Language barriers:** insufficient language specific information and lack of translation and interpretation services are perceived to be major barriers to accessing services.
- **Stereotyping:** some health and social care professionals continue to stereotype BME carers often having perceptions that they “look after their own” and assume that BME carers do not wish to access carers’ support services.

⁹² entitled “*Challenging the Myth: They Look After Their Own*”. *Black and Minority Ethnic Carers*.

- **Lack of knowledge:** the health and social care system is complex and often many BME carers are confused about where to go to for assistance.

There is clearly a need for further research to be commissioned into the experiences and needs of BME carers and care-recipients in Northern Ireland. A report into the needs of Chinese older people in Northern Ireland, for example, reveals that many are reluctant to access day care services due to language and cultural barriers (South & East Belfast Trust Report). The inability of people to access care services must inevitably have a profound impact upon their carers' health and emotional wellbeing. It is important that greater attention is given to the lives of BME carers in Northern Ireland in order to facilitate equity in access to the range of services which are available.

A number of recommendations have been identified by the Welsh Assembly Government report for improving service access for BME carers:

**Recommendations: BME Carers
(Welsh Assembly Government, 2003:10)**

- **Effective training on cultural diversity and ethnic monitoring to gain confidence in addressing carer assessments and professional gatekeeping issues.**
- **Consultation with, and where possible joint working with other providers and community advocates to develop trust and acceptance of BME carers.**
- **Insistence upon non-discriminatory approaches to service planning, care planning and carer assessment.**

The Carers of Children and Adults with Profound and Multiple Learning Disabilities

People with profound and multiple disabilities tend to have a degree of disability so severe that they need considerable assistance with all the basic tasks of living. This undoubtedly

places considerable pressure on their families and carers (Mencap, 2001:4).

This point is effectively illustrated in a report published by Mencap entitled, *“No Ordinary Life” (2001)*, which provides an account of the difficult and stressful lives lead by the families and carers of people with profound and multiple learning disabilities across the UK. The report highlights that often there is a mismatch between what families and carers need and what services actually deliver. The report further reveals that many of the experiences related to them by the families of people with profound and multiple learning disabilities, illustrates an overwhelming fundamental denial of human rights. Both in terms of the human rights of the person being cared for, but also the rights of families and carers (Mencap, 2001:3).

Key findings from the report which demonstrate the barriers to accessing appropriate services experienced by the carers and families of people with profound and multiple learning disabilities include:

- **A lack of understanding by service providers:** many parents felt that the caring tasks carried out within their homes was not fully understood by professionals. The report revealed that 60% of parents in the Mencap survey spent more than 10 hours per day on basic physical care and 57% spent more than 8 hours per day on therapeutic and educational activities. Often parents were woken up an average of three times per night with many parents believing that service providers were sometimes dismissive of the lack of sleep they frequently experienced (2001:10).
- **Day Care:** day care services were not always available on a daily basis. Many families reported difficulties in accessing day care services which met the specialist needs of people with profound and multiple learning disabilities (2001:28).
- **Respite Services:** residential respite services were highly valued, however, many families were experiencing considerable difficulties in accessing high quality, safe respite care (2001:15).

The Mencap report further identifies that there are many areas in which improvements should be made in regards to supporting

people with profound and multiple learning disabilities and their carers. These issues relate to diagnosis, the co-ordination of services, staff skills and attitudes, the provision of information, waiting for services and problems experienced during transition periods:

- **diagnosis:** parents reported that they often were “kept in the dark” about their child’s condition, many also felt that the treatment they received from some health care professionals was abrupt or insensitive. Only 4% of the parents participating in the study felt their child’s diagnosis had been explained to them appropriately (2001:22).
- **co-ordination of services:** people with profound and multiple learning disabilities were often dependent on a range of services provided by health and social services, the education sector and a range of voluntary organisations. The majority of parents in the study believed that services were poorly or very poorly co-ordinated and highlighted the need for a multi-agency key worker system (2001:23).
- **staff skills and professional attitudes:** many parents were critical of the attitudes of some professional and frontline staff. One of the most shocking findings of the survey was the extreme lack of value placed on people with profound and multiple learning disabilities. Most parents believed that they were not given the opportunity to be fully involved in the decision-making process regarding their child’s life. Many families commented upon the lack of training and skills of some staff in dealing with people with profound and multiple learning disabilities (2001:24).
- **information:** the lack of specially tailored, high quality, accessible and timely information was consistently highlighted as a problem by parents. The study revealed that carers needed to obtain a wide range of information about services and how to access them. For example, information on how to obtain an assessment, information on what services are available, information on benefits and on the complaints procedure (2001:26).
- **assessment and the provision of services:** the majority of parents expressed dissatisfaction with the assessment

believing that it was not thorough enough, was not reviewed as frequently as it should and did not deliver the services they required. Many parents reported that the assessment process did not take into account their needs or the needs of other family members (such as siblings) (2001:26)

- **fighting for services:** families often reported lengthy struggles to obtain the services they needed. Some reported that their constant struggle for services sometimes impacted negatively upon their relationship with their child (2001:28).
- **waiting for services:** many families experienced the problem of long waiting periods for essential services such as aids and appliances (2001:29).
- **transition:** many parents felt that they were not adequately supported when their child moved from children to adult services (2001:29-30).

The Mencap report suggests that people with profound and multiple learning disabilities and their families are often denied even basic human rights. The report makes a number of recommendations for ensuring that they and their carers are given a real choice in how they wish to live their lives. A number of these recommendations are outlined below, however, it is recommended that the DHSSPS and its associated bodies take into consideration all the recommendations and findings of the report.

Recommendations: The Carers' of Children and Adults with Profound and Multiple Learning Disabilities (Mencap, 2001)

- **Social Services, health and other agencies should ensure that carers are actively involved in the design and delivery of services and in tailoring individual packages of care. Carers' views should be recorded and used in the planning and commissioning of services.**
- **Social Services, health and other agencies should have a dedicated team sufficiently trained to understand the needs**

of people with profound and multiple learning disabilities. The team should have the understanding, skills and experience to carry out initial assessments, provide and review service provision and ensure that services are co-ordinated between different agencies.

- **Research should be commissioned into the additional cost of caring for children and adults with profound and multiple learning disabilities. Research should also focus on the numbers and specific needs of children and adults with profound and multiple learning disabilities.**

Carers of People with Mental Health Problems

The carers of people with mental health problems are affected by the traditional under funding of mental health services. Yet, there appears to be very little information on the experiences of carers of people with mental health problems in Northern Ireland.

A survey by Rethink⁹³ (2003) reveals that “patient confidentiality” (that is, maintaining the privacy and confidentiality of the service user) is one of the most frustrating barriers experienced by carers of people with mental health problems whilst attempting to access and use health and social care. Additional problems highlighted by carers include the inability to find an inpatient hospital bed or obtaining appropriate housing in the community for the person they care for.

The Rethink report (2003) further suggests that carers who support individuals with schizophrenia are less likely to receive services and support than people who provide care for an individual with another type of mental illness (for example, severe depression). Thus indicating the possibility of inequity of access to services amongst service users and carers according to the type of mental health problem. Additional difficulties identified by carers included a need for greater access to information on issues such as medication, specific mental health problems, the availability of new treatments, local service provision and coping strategies.

⁹³ the UK’s largest charity for people with severe mental illness.

As there appears to be little available information on the carers of people with mental illnesses in Northern Ireland it is strongly recommended that research be commissioned to identify barriers in accessing and using health and social services.

Kinship Care and Foster Care

Kinship Carers

Kinship care is a highly under-researched area in which little research is available on the lives of children living in kinship placements (Broad et al, 2001; Lernihan, 2003). Furthermore little is known about the kinship carers themselves or their help and support needs.

Broad et al (2001) define kinship care as, *“a child living away from the parental home with a relative or friend with the knowledge of the social services department, who would otherwise be with stranger foster carers, in residential care, independent living, or adopted”*.

A workshop report on kinship care produced by “Research in Practice” (2002)⁹⁴ highlights that children and carers in kinship care arrangements tend to receive less support, less services and less resources than those in foster care arrangements. The report further reveals that there are also variations in practice in regards to how social services assess, support and train kinship carers across different locations. The report also highlights that policy which specifically relates to kinship care is somewhat lacking and that where policies do exist they are usually “tacked on” to general foster care policy.

It is imperative that health and social care providers recognise the experiences and needs of kinship carers. The Research *in Practice* report makes a number of recommendations for improving kinship carers access to services (outlined below). It is vital that the DHSSPS and associated bodies take note of the emerging research on kinship care (particularly Northern Ireland-based research) and develop appropriate policies to respond to the needs of kinship carers.

⁹⁴ **Research in Practice** is run by the Association of Directors of Social Services, the University of Sheffield and over 80 participating local authorities and voluntary child-care organisations.

Recommendations: Kinship Care (Research *in Practice*, 2002)

- **Kinship care should be awarded equal status to other forms of care. The profile of kinship care should be raised as a distinct service type. This should include some form of public awareness campaign offering information and publicity on kinship care.**
- **More financial support should be available for kinship care.**
- **Information, advice and training for kinship carers should be made more widely available.**
- **An assessment of the data held on kinship carers should be conducted to identify the nature and extent of kinship care.**

Foster Carers

The latest survey by the Fostering Network reveals that 350 foster carers are urgently needed in Northern Ireland. Issues have been raised regarding the low status given to foster carers and their access to, and adequacy of, foster care allowances.

The Fostering Network argues that the shortage of foster carers will only begin to be addressed when carers receive an appropriate allowance which adequately covers the costs of fostering. The foster care allowances paid by all four HSS Boards in Northern Ireland have traditionally been lower than those paid in England (although efforts have been made to narrow the difference between local payments and national recommended allowances) (DHSSPS, 2002). However, the DHSSPS has acknowledged the need for greater investment in fostering services in order to provide better support for foster carers.

Carers and Human Rights

There appears to be a scarcity of literature which explicitly examines how policy and practice impacts upon the human rights of carers. The availability of such research is vital as it can be argued that the human rights of carers are placed secondary to those of the care recipient.

It is vital, for a number of reasons, that much greater attention be given to exploring the human rights implications of health and social care policy and practice for carers. Firstly, the human rights of carers and care recipients may at times be in conflict with each other and it is therefore crucial that legislation and policy must ensure that the potential for such conflict is kept to a minimum⁹⁵ (Rethink website). Secondly, it is important to raise the profile of the human rights of carers because they often act as advocates for the human rights of those to whom they provide care.

Article 3 of the ECHR (the right to protection for inhumane or degrading treatment) is perhaps the most important human right in relation to carers and is arguably the human right which is most frequently contravened. Numerous examples have already been provided in this section which demonstrate that carers are not always afforded the dignity and respect they deserve (for example, the level of deprivation, both financial deprivation and sleep deprivation, experienced by many carers and the negative and prejudicial attitudes towards carers displayed by some health and social care staff).

It is clear that there are many circumstances in which the human rights of carers are compromised by health and social care legislation, policy and practice and it is therefore vital that greater attention is paid to identifying and addressing these issues.

⁹⁵ An example of the potential conflict between the rights of carer and care recipient could arise in the case of a mental health services users' right to privacy and confidentiality (Article 8 of the European Convention on Human Rights) in regards to treatment and medication, versus a carers' need for that information to provide effective and efficient care.

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Useful Web-Links*

- **Belfast Carers Centre** - provides support and information to Carers across Belfast and the Greater Belfast area, part of the Princess Royal Trust for Carers network.
www.carerscentre.org
- **Carers Information Network** – group of organisations working in partnership to provide support and information for carers in Belfast.
www.carersinfo.net
- **Carers UK** – a carer led organisation which provides a voice for carers.
www.carersuk.org
- **Cause** – a Northern Ireland charity and community mental health agency which provides support and education for the relatives and carers of people with mental illness.
www.cause.org.uk
- **Crossroads** – provides home based respite care services for carers in Northern Ireland.
www.crossroadscare.co.uk
- **Gingerbread** – leading support organisation for lone parent families in the UK - www.gingerbread.org.uk
- **National Family & Parenting Institute** - The National Family and Parenting Institute (NFPI) is an independent charity working to support parents in bringing up their children.
www.nfpi.org
- **Parents Advice Centre** – voluntary organisation that offers support, guidance and counselling to parents and young people with family difficulties.
www.pachelp.org

- **Princess Royal Trust for Carers** – largest provider of comprehensive carers' support services in the UK.
www.carers.org
- **Young Carers** – Princess Royal Trust for Carers Young Carers website.
www.youngcarers.net

* Please note that this is NOT a definitive list of relevant websites