

# **Older People's Experience of Health Services in Northern Ireland**

**Help the Aged, Office of the First and Deputy First  
Minister and the Northern Ireland Human Rights  
Commission**

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This research document is available on the Northern Ireland Human Rights Commission's website ([www.nihrc.org](http://www.nihrc.org)) as a discussion paper. The document does not necessarily reflect Commission policy.

*Health is a fundamental human right*

*Indispensable for the exercise of other human rights.*

*Every human being is entitled to the enjoyment of the highest*

*Attainable standard of health conducive to living a life in dignity.*

UN, Economic and Social Council, E/C. 12/2000/4, CESCR, General Comment, 14.

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## 1.0 Executive Summary

This study was commissioned by Help the Aged, Office of the First and Deputy First Minister in partnership with the Northern Ireland Human Rights Commission to explore older people's experience of health services specifically having regard to protection and promotion of their human rights. Age discrimination can be direct, occurring when a person is treated less favourably than others because of their age. Indirect discrimination occurs when older people are disadvantaged because they are disproportionately affected in comparison to the rest of the population.

A qualitative approach was used to examine the nature and variety of experiences of older people. Older people were accessed via community groups, senior citizen groups, Help the Aged, Age Concern, and health trusts. Following extensive fieldwork, 27 older people within individual and paired interviews were finally interviewed. Consultations took place with staff from HPSS (Health & Personal Social Services). These consultations were conducted to discuss issues raised within interviews. Further consultation with HPSS staff would have been desirable; however, because of resource limitations there was insufficient time to do so. The comments of professionals are treated as anecdotal as this group was not formally interviewed as respondents in this study.

It must be noted that the evidence presented in this study does not include the evidence provided by older people of good practice among HPSS staff, in which they were presented as being caring, professional, often going beyond their duty. As this report is based on interviews with older people, it cannot objectively prove breaches of human rights. However, the experiences portrayed by older people give rise to concerns on a number of issues related to:

- Possible breaches of the European Convention on Human Rights such as Article 3, which prohibits degrading or inhuman treatment; Article 8, the right to privacy; and Article 14 the right not to be discriminated against in the availability of the other Convention rights. In particular, the report highlights the crucial and complex issue of the State's positive obligations to ensure that older persons do not endure degrading or inhuman treatment arising from the conduct of others or generally, and that they do not endure interference with their personal, family or homes lives, even though such interference has not been directly occasioned by the State. The issue of how a State complies with its positive obligations to protect human rights is one which is still in development and likely to be a topic of immediate concern for some time.

Particular criticisms included:

- Lack of information so as to gauge standards of care and raise expectations
- Racism
- Waiting times in both community and secondary / acute care
- Accessibility of transport
- Complaints procedures

Valuable lessons from previous research are summarised in a review of UK literature of discrimination in the HPSS.

In conclusion, older people in this research displayed low expectations which can be linked to a lack of standards of health care which are not actively disseminated and provided. Unless standards or targets are provided for older people, judgements on the quality of care and entitlements cannot be made. HPSS staff have alluded to inequalities in health care delivery and the literature has highlighted how older people are directly or indirectly discriminated against. Only through further research can organisational / unwritten policies that discriminate against older people be uncovered. The following main recommendations should address some of the outstanding issues raised within this report:

- In order to further identify the causes and effects of discrimination of older people in the health care system further research is required to establish the perceptions and socially held beliefs about how older people are valued and as a result, treated when health services are delivered to them. The way in which caseloads are prioritised particularly within acute or secondary care and specialisms of cardiology should be investigated. This approach would require independent clinical review with the support of health trusts, particularly acute health trusts.
- Clear benchmarks for the quality and standards of care are required so that older people are aware of the standards they should expect. Targets for the delivery of health services to older people are required in order to gauge the impact of TSN (Targeting Social Need) and Department Health Social Services Public Safety (DHSSPS) Priorities for action. These could take the form of quality standards for the delivery of treatment within specialisms (information could include expected waiting times, prioritisation policies, case review, etc). The DHSSPS has advised the Commission that such work is underway.

Preparatory work has already begun in England via the National Service Framework (NSF) for Older People. Policy makers should take cognisance of the approaches already begun to address discrimination within the NSF Policy Audit with a view to using similar approaches within Northern Ireland, such as focussing on the impact of older people of **unwritten** and written policies. This type of approach could be brought forward by DHSSPS, voluntary / community groups and health trusts. As part of this, health trusts should review all policies with age-based criteria to establish if there is sound clinical evidence for age-based rationing. This takes place 'in-house'. However, an external critical review could ensure that all such policies have been thoroughly reviewed.

- This research has only 'scratched at the surface' of the applicability of human rights principles to the provision of health and social services to older people. In order to assess whether human rights principles are being observed in the delivery of health and social services to older persons it would be necessary to inform older people of their rights and entitlements via the Northern Ireland Human Rights Commission (NIHRC), older people's groups or Citizens Advice Bureaux. On creating greater awareness, older people may feel more empowered to challenge and question clinicians' decisions, complain and if required seek guidance from support agencies.

- It is necessary to encourage those who feel that they have been discriminated against or treated, in a manner which may suggest a breach of their human rights to come forward. This can only be done through an effective and non-threatening complaints procedure. As a result, further work is required by the DHSSPS to review and possibly restructure the complaints procedures in place. However, until the outcome of such a review, Section 75 grounds should be used to monitor complaints. Results should be published.

## 2.0 Aims of the Study

The aim of this study was to review the experiences of health care by older people in light of HPSS policies and the rights of older people. For the purposes of this study, people over the age of 60 were targeted.

The terms of reference stipulated that older people should be interviewed about their experiences of health care. In particular, the steering group was particularly interested in and wanted to focus on older people's experience of the following areas:

- **Rural isolation and access**
- **Double or multiple discrimination (discrimination against the same person on a number of grounds is often known as multiple discrimination though there is no definitive term for this phenomenon)**
- **Decline / not treat on basis of age**
- **Lack of services and expressed needs**
- **Mismatch between services available and expressed needs**

From the outset the main thrust of the research was based on evidence gathered from descriptions about the relevant areas in question (see Appendix A for interview schedule).

## 3.0 Methodology

It was proposed that respondents would be accessed via community groups and forums such as senior citizens clubs. On that basis, 103 groups (52 groups in the Newry and Mourne area and 51 in North and West Belfast) were contacted and asked to take part in the research. Only a limited number (seven groups in total) indicated an interest in participating in the research. A further seven groups, of which two were Forums (whereby 30-40 representatives from older people's groups attended), were also contacted.

Following visits to 14 groups who agreed to take part in the research, seven individual interviews took place, four group interviews took place with 13 people in four groups, and a paired interview took place with a couple. A telephone interview was also conducted with one respondent.

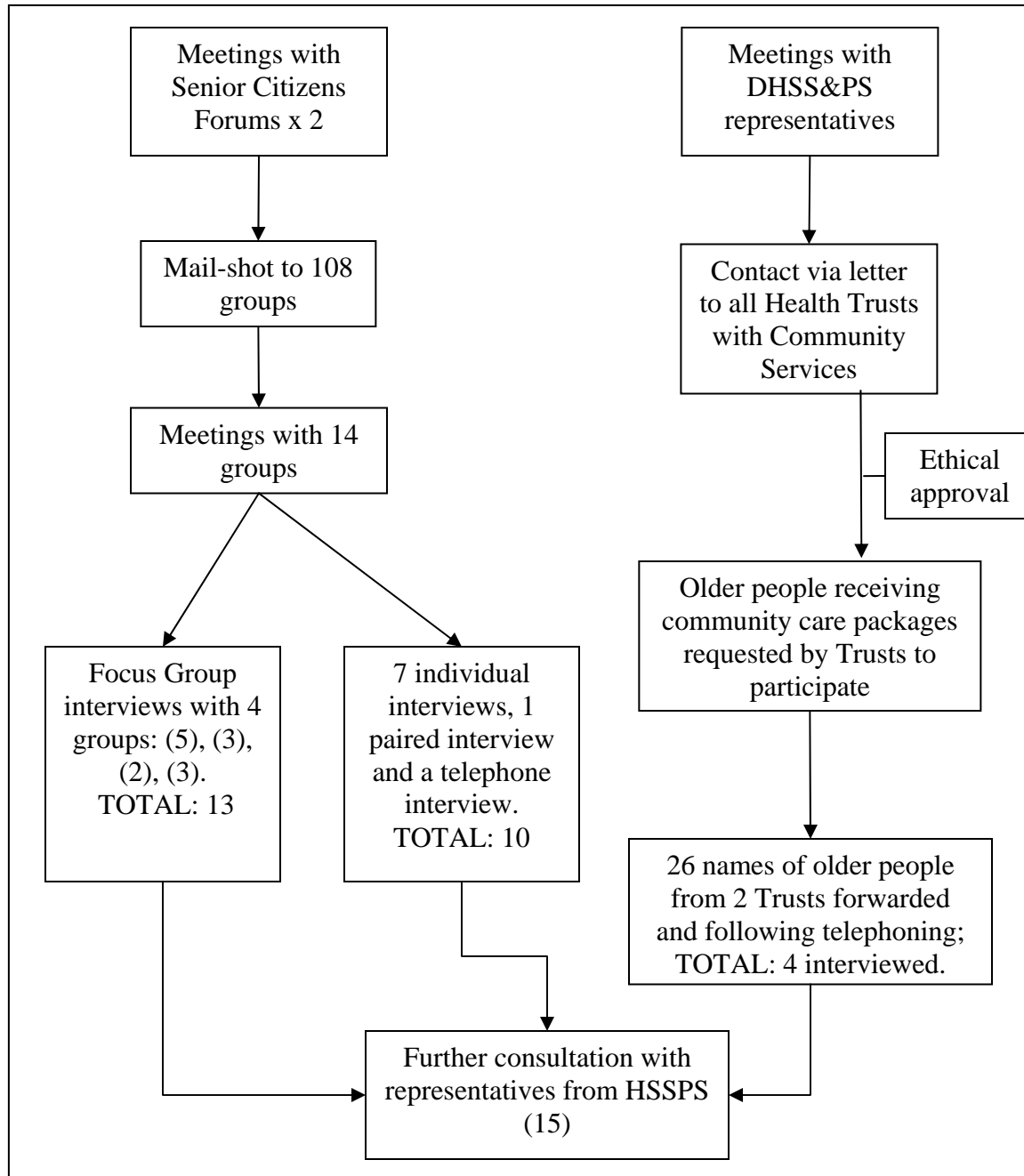
In order to access those who could be considered to be heavier users of health care services, HPSS trusts providing community health services to older people were asked to select a random sample of those receiving care packages and request their client's participation in the research. Two trusts



supplied names of clients (given with their permission) between February 2002 and April 2002. A further four trusts also supported the research but due to deadlines for fieldwork there was insufficient time to enable them to assist.

The methods by which older people were invited to be involved in this research are illustrated in the following diagram:

**Fieldwork approach**



On contacting 26 individuals who are currently receiving care packages, a further four individuals were selected for interview. The issues highlighted were similar to those issues raised by groups and individuals accessed via the voluntary and community sector. However, there was a higher concentration of relevant issues highlighted by the experiences of older people who are currently receiving complex care packages. Interviews were conducted with older people throughout all health board areas; 11 Southern, three Northern, six Western and seven Eastern.

All respondents were assured of anonymity and the experiences they relayed within interviews and focus groups remained confidential. All respondents were requested to sign a consent form and the conditions of disclosure were discussed with each of the respondents (see Appendix B for consent form). In this report therefore, respondents' real names are not used. Each interviewee has been coded, and in some cases, so as to personalise the experience, aliases are used.

### **3.1 Limitations of the Study**

This study focuses on assessing older people's views, experiences and descriptions of how they felt healthcare providers treated them. Rather than uncovering if discrimination occurs, this study investigated if older people had personal experience of discriminatory practices within the HPSS. To establish if discrimination, either direct or indirect, occurs within the HPSS, the terms of reference would need to be broadened to allow:

- An independent review of discrimination in each case as it arose.
- Further investigation into health professional's attitudes and practices to establish the extent and variability of age discrimination within healthcare provision.

As indicated in the methodology a large number of groups were approached so that a range of older peoples' experiences could be recorded. It was anticipated that a larger number and a greater variety and depth of experiences could be obtained through interviews. However, when conducting fieldwork many older people compared services now to the way they were many years before, indicating vast improvements, rather than focussing on current problems or difficulties that they had encountered. Few older people interviewed critically reviewed services in terms of their rights or the standards and there was in this study, an acceptance of waiting *per se* for services (see pages 57 and 67).

It must be noted that many older people throughout the fieldwork and those within interviews expressed gratitude and praised health providers for the services that they have received in the past.

### **4.0 Northern Ireland Context**

This study took place at a time of an ever-changing political climate whereby resulting local policies have been developed and enhanced specifically for local needs. Section 75 of the Northern Ireland Act 1998 places a statutory duty on the HSSPS to promote equality of opportunity and to ensure that policy makers are aware of equality implications of all policies at all

stages. Further, this equality legislation forces the HSSPS to tackle equality issues within policies and working practices.

In 2001 (30 June), it was estimated that there were 262,211 older men (aged 65 and over) and older women (aged 60 and over) in Northern Ireland representing 16.6% of the total population. At present, the majority of social service clients are older people. Of the 165,000 adults in 2001-2002 who had contact with social services welfare, 80% were above 65 years of age.<sup>1</sup>

The number of over 65s will increase in Northern Ireland by 17% between 2000 and 2015. The number of older people (aged 85 and over) will have almost doubled within the next 20 years. Some Health and Social Services Board Areas can expect a greater increase in the percentage of older people. For instance, the Western Health and Social Services Board area will expect a 24% rise whereas the Eastern area will expect a 9% rise.<sup>2</sup>

Evidence indicates that health inequalities increase with age:

*“Health inequalities increase with age. Older people suffer a disproportionate burden of ill-health in society. Lower incomes, living in older less well heated properties and social isolation all contribute to the health burden on the elderly.”*<sup>3</sup>

As a result of demographic changes, it is expected that with the increase in an ageing population, there will be an increase in those with long term medical problems. 40% of health care is consumed by older people even though they constitute 16% of the population (Office for National Statistics, 2001). At any one time, two-thirds of hospital beds are occupied by patients over 65 however, research indicates that the heaviest use of hospital resources occurs during the final months of life regardless of age.<sup>4</sup> In Northern Ireland, the average hospital and community health service cost to the NHS of a person aged over 85 is just over five times the cost for a 16-44 year old and nearly four times the cost for a 45-64 year old.<sup>5</sup> Therefore, it is expected in the coming decades and as a result of changing demography, the costs of caring for older people will rise.

It is expected that an increasing ageing population will put a strain on the provision of timely and sufficient health care. The following quotation highlights some of the dilemmas of targeting resources:

*“As resources are limited; not all that is desirable can be done. If resources are used in one way (for example, providing more physiotherapy for handicapped people) they cannot be used in other ways (such as screening for Down’s syndrome or providing more hip replacements). Thus, in this example, providing benefit for handicapped people means giving up the chance to give benefits to pregnant women or elderly people. Whatever the best alternative use is judged to be, it is the benefits given up in that use that represent the ‘opportunity cost’.”*<sup>6</sup>

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<sup>1</sup> McWhirter 2002.

<sup>2</sup> McWhirter 2002.

<sup>3</sup> O’Reilly and Gaffney 2001 p10.

<sup>4</sup> Himsworth and Goldacre 1999.

<sup>5</sup> McWhirter 2002.

<sup>6</sup> Mooney *et. al.* 1992.

The realities of providing services at cost, or opportunity cost is not readily acknowledged within policy documents. Providing quality services and targeting investment to address needs is heralded within many of the DHSSPS policies developed. For instance, the 2001 New TSN framework aims to skew resources to those most in need, for example those in poor health or socially excluded. As a result, it is proposed that services will be targeted to older people who are disadvantaged, either socially or economically.

In England and Wales the National Service Framework for Older People (2001) indicates that the “NHS will be provided, regardless of age, on the basis of clinical need alone”. The framework suggests greater investment “into those services which are particularly more important for older people such as cataract surgery, joint replacement and community equipment is essential so that people have fair access to these services as well as the full range of specialist services”.<sup>7</sup>

Although the Government recognises the need for resources and development of services for this ageing population, the deployment of resources comes at a cost. The impact of unmet need of older people is outlined later in this study. Before examining the issues central to this research, the following section outlines the human rights legislation that applies in the area of older people and health.

## **5.0 Human Rights and Equality**

- *Enhancing the Rights of Older People in Northern Ireland* (NIHRC, 2001) outlined the various ways in which the rights of older persons to certain standards of health and social care are protected generally. The human rights instrument of most immediate impact is the Human Rights Act 1998 (HRA), which incorporates the European Convention on Human Rights (ECHR) into domestic law. The Convention rights protected in the HRA can be pleaded in any court. While the chief focus in this section is on the HRA, other applicable human rights and equality instruments are also mentioned.
- Particular aspects of the Human Rights Act are discussed and explained here to provide the reader with an opportunity to appreciate the manner in which the Act operates. However, at appropriate points later in the report, the applicability of the Human Rights Act is discussed to provide the reader with concrete examples of the manner in which the Act applies to the delivery of health and personal social services to older people.

### **5.1 Positive Obligations**

The Convention places obligations on the State to act positively to secure rights, rather than merely refrain from infringing them (the latter being described sometimes as negative obligations). The crucial issue, for the courts and HPSS service providers, in future years will be the extent of such positive obligations on the State, particularly in respect of Articles 3 and 8.

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<sup>7</sup> See p 16.

- Strasbourg jurisprudence has yet to provide detailed guidance on determining the content of positive obligations though there has been some consideration of the scope of such obligations in some cases. For example, in *Lopez Ostra v Spain*,<sup>8</sup> the European Court of Human Rights considered that a duty existed to take reasonable measures to prevent severe environmental pollution from having an adverse effect in the private life of a family living in the vicinity. And in *Botta v Italy*,<sup>9</sup> though the Court rejected the complaint that the failure of the state to enforce a law that required bathing facilities at the beach to be accessible to persons with disabilities was a breach of the complainant's Article 8 rights, it did recognise that 'in exceptional cases where a lack of access to public ... would prevent her right to personal development' that Article 8 would apply. As a result, the domestic courts have been left to apply the concept of positive obligations to concrete situations and the law could be said to be in a state of development or evolution.
- In *R (Bernard) v Enfield London Borough Council*<sup>10</sup> Sullivan J concluded that the failure by the respondent council to provide suitably adapted accommodation for the applicant and her family amounted to a violation of her Article 8 rights, though he did not consider that the circumstances she was forced to endure as a consequence of this failure did not give rise to such severity of ill-treatment as to reach the Article 3 threshold. The applicants were husband and wife, and they resided with their six children. The wife had a disability which required her to use a wheelchair. She was doubly incontinent and as there was no wheel chair access to the lavatory she was constantly soiling herself. Living conditions were cramped and she had no privacy and could not participate in the rearing of her children.<sup>11</sup> The Council accepted that it was in breach of its duty under section 21(1) (a) National Assistance Act 1948. Sullivan J considered that following assessments of the female applicant by the Council it 'was under an obligation not merely to refrain from unwarranted interference in the claimants' family life, but also to take positive steps including the provision of suitable adapted accommodation, to enable the claimants and their children to lead as normal a family life as possible, bearing in mind [the wife's] disabilities'. And later, 'The Council's failure to act on the September 2000 assessments showed a singular lack of respect for the claimants' private and family life. It condemned the claimants to living conditions which made it virtually impossible for them to have any meaningful private or family life for the purpose of Article 8. Accordingly I have no doubt that the defendant was not merely in breach of its statutory duty under the 1948 Act. Its failure to act on the September 2000 assessments over a period of 20 months was also incompatible with the claimants' rights under Article 8 of the Convention'.
- The decision in *Bernard* has been considered by the Court of Appeal in England in conjoined appeals involving claims by asylum seekers: *Anufrijeva v Southwark LBC*, *R (N) v Secretary of State for the Home Department* and *R (M) v Secretary of State for the Home Department* (hereafter referred to as 'Anufrijeva').<sup>12</sup> The Court of Appeal did not disapprove of the determination made by Sullivan J in *Bernard* and accepted that it was

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<sup>8</sup> (1994) 20 EHRR 277.

<sup>9</sup> (1998) 26 EHRR 241.

<sup>10</sup> [2002] EWHC 2282 Admin.

<sup>11</sup> This description of the female applicant's situation is taken from the Court of Appeal's judgment in 'Anufrijeva.'

<sup>12</sup> [2003] EWCA Civ 1406, [2003] All ER (D) 288 Oct, Decision of 16<sup>th</sup> October 2003.

open to him to arrive at the conclusion he did on the facts. It did, however, provide further detail on how Article 8 might be applied in cases where it is asserted that a failure to provide health and social care services has resulted in a breach of the states' positive obligations. Such detailed views include the following:

- In respect of complying with their positive obligations to have respect for a person's Article 8 rights, the state has wide margin of appreciation in determining the steps to be taken to ensure compliance with the Convention.<sup>13</sup>
- In both the negative and positive contexts, regard must be had to the fair balance which has to be struck between the competing interests of the individual and the community, including other concerned third parties and the state's margin of appreciation.<sup>14</sup>
- Before inaction can amount to a lack of respect for private and family life, there must be some ground for criticising the failure to act. There must be an element of culpability. At the very least, there must be acknowledgement that the [applicant's] private and family life was at risk. Where the domestic law of a State imposes positive obligations in relation to the provision of welfare support, breach of those positive obligations of domestic law may suffice to provide the element of culpability necessary to establish a breach of Article 8, provided that the impact on private or family life is sufficiently serious or was foreseeable.<sup>15</sup>
- It is not necessary for a public authority to have so far departed from the performance of its duty as to amount to a denial or contradiction of that duty before Article 8 will be infringed.... [I]t is necessary to have regard both to the extent of the culpability of the failure to act and to the severity of the consequences. Clearly, where one is considering whether there has been a lack of respect for Article 8 rights, the more glaring the deficiency in the behaviour of the public authority the easier it will be to establish the necessary want of respect. Isolated acts of even significant carelessness are unlikely to suffice.<sup>16</sup>
- In short then, whether there has been a violation of the state's positive obligations under Article 8 will depend on the circumstances, and even where statutory duties are not observed this will not always amount to a breach of Article 8 unless the facts are similar to those in *Bernard*.

## 5.2 Applicability to Public Authorities and Private Bodies

Section 6, of the HRA places an obligation on "public authorities" to act in a way that is compatible with the European Convention on Human Rights and makes it unlawful for a "public authority" to act in a way that is incompatible with the European Convention. Sections 2 and 3 require courts and tribunals to take relevant European Convention Human Rights Law into account

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<sup>13</sup> The Court of Appeal cited the European Court of Human Rights in *Abdulaziz v UK* (1985) 7 EHRR 471.

<sup>14</sup> The Court of Appeal cited the European Court of Human Rights in *Glass v UK* (2001) 33 EHRR I.

<sup>15</sup> At paragraph 45.

<sup>16</sup> At paragraph 48.

when making decisions and to interpret legislation in a way that is compatible with the European Convention.

Identical obligations to those placed on public authorities are placed on those private bodies 'certain of whose functions are functions of a public nature' (Section 6(3) (b)). As one would expect, all health and social services authorities are considered to be public authorities for the purposes of the HRA. The ambiguity in the application of the Act arises in respect of private bodies which, in fulfilling the terms of a contract with a public authority, are delivering health and personal social services to the public. Significant use is made of such contractual arrangements to deliver services to various client groups, not just the elderly. In order for the HRA to apply to such a private body the courts must conclude that it is carrying out 'public functions'. There has been some judicial consideration of this difficulty already. The Court of Appeal in England considered that the Leonard Cheshire Foundation (LCF), in fulfilling a contract made between it and a local authority to provide accommodation services for the authority, thereby allowing the authority to fulfil its statutory duty,<sup>17</sup> was not performing public functions under the Human Rights Act.<sup>18</sup> The fact that LCF was receiving public funding was not enough to determine whether the functions were public or private. The Foundation was not performing statutory powers, nor did the fact that the authority was acting under statute confer powers on the Foundation. LCF was not, the court concluded, 'standing in the shoes of the local authorities'.<sup>19</sup>

In another case, *Poplar Housing and Regeneration Community Association Ltd v Donoghue*,<sup>20</sup> a tenant of the housing association was resisting eviction on the basis that eviction interfered with her right to family life, under Article 8. The main issue for the Court of Appeal was whether the Housing Association was performing public functions. The association was not a public body merely because it performed activities on behalf of a public body, in this case a local housing authority. But the Court did consider that on this occasion the association's activities were so closely assimilated to those of the local housing authority to justify the conclusion that it was a 'functional public authority'.<sup>21</sup> The housing association was set up by the local authority to take the transfer of some of its housing stock and some of the local authority members were also members of the housing association. Thus the HRA applied to the housing association.<sup>22</sup>

And in *R (A) v Partnerships in Care Limited*<sup>23</sup> a private psychiatric hospital was a public body for the purposes of the Human Rights Act, because it was operating to certain statutory requirements effectively delegated to it in its contractual arrangements with the relevant health authorities.

Clearly this is a very significant issue for the social care sector and service users. The identity of the service provider, and the basis on which the service provider is providing the service, may determine whether the Human Rights Act applies or not.

### **5.3 Selected Convention Rights of Particular Relevance to Older People**

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<sup>17</sup> under section 21 of the National Assistance Act 1948.

<sup>18</sup> *R (Heather) v Leonard Cheshire Foundation* [2002] 2 All ER 936.

<sup>19</sup> *Ibid* at p 945.

<sup>20</sup> [2001] 4 All ER 604.

<sup>21</sup> *Op. Cit.* at p 621.

<sup>22</sup> See also *Aston Cantlow and Billesley Parochial Council v Wallbank* [2001] 3 All ER 393.

<sup>23</sup> 2002 (5) CCLR 330.

- Article 3 stipulates the right not to be subjected to inhuman treatment and provides that “*No-one shall be subjected to torture or to inhuman or degrading treatment or punishment*”. Torture is the most severe form of ill-treatment and degrading treatment is the least severe. Not all forms of ill-treatment will infringe Article 3. In order to engage the Article treatment must meet the test for degrading treatment, namely ‘treatment that arouses in the victim a feeling of fear and anguish and inferiority capable of humiliating and debasing the victim and possibly breaking his or her physical or moral resistance.’<sup>24</sup>
- Lord Hunt indicates that in the area of health, specifically where an older patient has a living will stating that he or she does not want to be resuscitated or have his or her life maintained through enforced treatment and the right not to be treated – his or her right not to be subject to degrading treatment under Article 3 may be violated.<sup>25</sup>
- Article 3 might also be infringed if social workers became aware of an older person who was enduring ill-treatment at the hands of another, but failed or refused to intervene to alleviate the older person's suffering, drawing an analogy with *ZP and TM v UK*,<sup>26</sup> where the European Court considered that the failure by social services authorities to apply to the courts to have children taken into care where they were clearly suffering horrendous abuse and neglect was a breach of their Article 3 rights.<sup>27</sup> Any intervention by social workers or other social care staff would have to be sufficient to discharge the State's positive obligations to protect the older person from Article 3-type harm.
- Article 8 protects a person's right to respect for home, family and private life. It states that “*Everyone has the right for his (or her) private and family life, his (or her) home and his (or her) correspondence*”. For example, if an older person is denied access to officially held information about his or her health, or private or family life his or her Article 8 rights may have been violated under Article 8.<sup>28</sup> Article 8 may have an impact on decisions to ration services which affect people's ability to remain in their own home or maintain social family relationships. It has also been pointed out that potential breaches of Article 2 and Article 8 happen when older people are forced to leave homes because of closures (NIHRC, 2001), though this view must now be examined in light of cases such as *Bernard and Anufrijeva* (discussed above).

Article 8 is not an absolute right, unlike Article 3 for example, and it is permissible for the State to interfere with this right if a number of conditions are met. The key principles (below) governing the scope of rights namely Article 8. Note that it is often suggested that a balancing exercise is being conducted by the courts when they assess whether the interference with a right is justified. However, this is not a full and accurate characterisation of the process. The state, in asserting that it has justifiably interfered with the exercise of the right, must discharge a heavy obligation, as the right-holder is presumed to be free to exercise the right.

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<sup>24</sup> Judgement of the European Court of Human Rights in *Ireland v United Kingdom* paragraph 167.

<sup>25</sup> Hunt 2000.

<sup>26</sup> Application NO 29392/95.

<sup>27</sup> A scheme for taking older persons into care exists under Article 37 and Schedule 6, Health and Personal Social Services (Northern Ireland) 1972, though there appears to be little information about its use.

<sup>28</sup> Hunt 2000.



- The interference must be in accordance with law, which is to say that it must have a lawful basis either in statute or in common law;
- It must also be ‘necessary in a democratic society’. This phrase has been interpreted as meaning that there must be a ‘pressing social need’ for the interference, meaning that there must be an identifiable reason for it or set of circumstances that justifies the interference;
- The interference must be for a legitimate aim or purpose, such as the protection of the rights of others, for example; and
- The interference must be a proportionate method of attaining that purpose. Not every interference will be justified therefore; only those necessary to achieve the legitimate aim or purpose.

Finally, in terms of setting the parameters of the acceptable degree of interference with the right, the state will be accorded a ‘margin of appreciation’. This principle allows the European Court on Human Rights to make a decision that it is inappropriate for it to interfere in the actions of national decision-makers, because those national decision makers are “in better position than the international judge to give an opinion in the exact content of those requirements as well as on the necessity of a ‘restriction’ or ‘penalty’ intended to meet them.”<sup>29</sup> State traditions and values are taken into account when applying this legislation.

- Article 14, the right not be discriminated, against states that “*The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status*”. Age is not formally mentioned in this list of impermissible discriminatory grounds. However, ‘other status’ affords interpretation to include other grounds of discrimination at present. Article 14 has further significant limitations in its application. It is not a free-standing clause and thus does not stand on its own as an anti-discriminatory provision. An individual can complain only about discrimination under Article 14 if other ECHR rights are being engaged, though it is not necessary that the other Convention right be violated.<sup>30</sup> Many services delivered to the elderly could be considered to engage Articles 3 and 8 because they are ways in which the state fulfils its positive obligations to allow older people the right to family and home life, or because such services ameliorate the pain, discomfort or anguish they ensure. Discrimination in the delivery of these services would give rise to issues under Article 14. Article 14 is further limited in its effect because, unlike direct discrimination in domestic equality law for example, it is possible to justify the discrimination thereby ensuring that there is no violation of Article 14. Discrimination can be justified if it pursues a legitimate aim in a proportionate manner.
- The right to life under Article 2 of the ECHR states that “*Everyone’s right to life shall be protected by the law*”. For example it has been suggested that there is an unwritten policy

<sup>29</sup> *Handyside v UK* 1976 1 EHRR 737.

<sup>30</sup> The UK has not signed or ratified Protocol 12 to the European Convention of Human Rights, which contains a free-standing anti-discrimination clause.

of Do Not Resuscitate (DNR) which is based on a patient's age.<sup>31</sup> This is obviously a breach of Article 2. However, Woogara indicates that the NHS has been able to limit life saving treatment to those most in need with the support of the court. In the case of *R v Cambridge Health Authority Ex Parte B*<sup>32</sup> Jayne Bowen was refused bone marrow transplant because of the costs. The Court of Appeal concluded that the court was not in a position to decide 'on the correctness of the difficult and agonising judgements which Health Authorities had to make, as how a limited budget was best allocated to the maximum advantage of the maximum number of patients'. As a decision that pre-dates the HRA, this issue would now have to be considered in light of the state's positive obligations to protect a person's right to life. However, whether the court would enjoin an HPSS authority to use its funds to prevent the death of an older person where the authority was reluctant or resistant to intervening is questionable. Further, where decisions have to be made, it is crucial that they can be justified and that decisions makers can demonstrate that they have taken Article 2 into consideration as part of the decision making process.

- Article 5 of the ECHR states that '*Everyone has the right to liberty and security of person*'. When 'informal' admissions are made for older people considered to be mentally ill there could be a breach of Article 5 because such admissions do not provide older patients with adequate procedural rights – his or her right to liberty may be violated (Hunt, 2000). One other possible breach might lie in Article 37 of the Health and Personal Social Services (Northern Ireland) Order 1972 which allows an older person to be taken into the care of an HPSS Authority, based on the procedure set out in Schedule 6. Although this is a little-used procedure, it could be the manner in which the state fulfils its Article 3 positive obligations and in any event it must comply with Article 5. The 'nearest' provision for this procedure in Article 5 is at 5(1) (e), which provides for the detention of 'persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants'. There is an issue as to whether the procedure in the 1972 Order complies with Article 5, because there is no specific reference in Article 5(1) (e) to persons who are incapable of caring for themselves.
- Article 6 (1) highlights the right to a fair hearing. "*In the determination of his civil rights and obligations... everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law*". In the area of social care, there is an issue to whether the complaints system concerning decisions complies with Article 6, assuming the issues involved are "civil rights and obligations". It appears that the internal procedure can be lengthy and a case may get as far as an independent review or Ombudsman but there is no power to compel a course of action or remedy for the complainant. It has been suggested that as the complainant may not therefore have an adequate appeal system, it may violate his or her right under Article 6(1) (NIHRC, 2001). However, the fact that the complainant has recourse to the courts in judicial review means that there is, prima facie, compliance with the Article 6 duty. The substantial issue, however, is whether judicial review would provide an adequate opportunity for the complainant to have his or her civil rights and obligation 'aired'. If not, there is a breach of

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<sup>31</sup> Woogara 2003.

<sup>32</sup> 1995 1 WLR 898.

Article 6. In *Runa Begum v Tower Hamlets LBC*,<sup>33</sup> the House of Lords considered that a person who was aggrieved about a housing decision made by the local authority could have recourse to the county court and that this sufficed for Article 6 purposes. The applicant had claimed that the requirement to avail of the local authority internal complaints mechanism, staffed as it was by authority employees, violated the right to a fair trial.

- Article 1, the right to property – everyone is entitled to the peaceful enjoyment of his possessions under Article 1, Protocol 1 of the ECHR which states that; “*Every natural or legal person is entitled to the peaceful enjoyment of his possessions. No one shall be deprived of his possessions except in the public interest and to the conditions provided for by law and by the general principles of international law*”. It might be the case that an older person would wish to challenge a decision of the Office of Care and Protection that the decision it had made to appoint a person to administer his or her property was a breach of this Article, or that the legislation under which it operated was incompatible with this Article. These challenges would be complex and difficult and might not have a strong chance of success, though it would take a very detailed analysis of the relevant statutes and case law to arrive at a more definitive conclusion. One other way in which this Article might be invoked relates to regimes for charging for services. Such charges arguably engage this Article and different approaches to charging across Northern Ireland, or the UK generally, might be a breach of Article 14, taken in conjunction with Article 1 Protocol 1.

#### **5.4 Section 75, Northern Ireland Act 1998**

One other significant provision in domestic legislation is section 75 of the Northern Ireland Act 1998, commonly referred to as ‘the statutory duty’. The specific terms of the main duty<sup>34</sup> are that in carrying out its duties a public authority is to:

*"have due regard to the need to promote equality of opportunity -*

*(a) between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;*

*(b) between men and women generally;*

*(c) between persons with a disability and persons without; and*

*(d) between persons with dependants and persons without."*

All HPSS authorities are subject to the duty. The section 75 statutory duty seeks to ensure equality of opportunity by requiring public sector organisations to assess, on a systematic basis, the manner in which they carry out their functions to see whether any inequalities arise from the body’s activities. The belief is that by placing the duty on public sector bodies to ensure equality of

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<sup>33</sup> 2002 EWHC 633.

<sup>34</sup> Subsection 1. Subsection 2 includes an ancillary duty: “Without prejudice to its obligations under subsection (1), a public authority shall in carrying out its functions relating to Northern Ireland have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group’. The relationship between the two subsections is not entirely clear. However, subsection 1 is stated in stronger terms than subsection 2.

opportunity in the manner in which they function, a more co-ordinated approach to achieving equality of opportunity can be maintained. Section 75 involves the public agency taking responsibility for ensuring equality of opportunity in the sphere of activity under its control. The approach taken is often referred to as 'mainstreaming equality', encapsulating the idea that the assessment of the impact of a public body's activities on equality of opportunity should occupy a central and continuing role in the management of the public body.

## **5.5 Equality Schemes and Equality Impact Assessments**

In order to comply with the statutory duty in section 75 a public body is first required to produce, on a quinquennial basis, a document known as an 'equality scheme'.<sup>35</sup> The purpose of the scheme is to demonstrate the manner in which the public body intends to fulfil the duties imposed on it by section 75. In compiling the equality scheme the public body will first have to determine which of its functions should be included in it. This process is commonly referred to as 'screening'.

There are a number of particular matters that must be adhered to in the equality scheme.<sup>36</sup> It must include reference to the mechanisms by which the public body intends to consult with the public on proposed policies and on amendments to existing policies that may have an impact upon the promotion of equality. It must also monitor any adverse impact changes in their activities might have on compliance with that duty.<sup>37</sup> The process of monitoring any possible adverse impact is conducted by carrying out an 'equality impact assessment' (EQIA), discussed below.<sup>38</sup> The results of EQIAs must be published and the equality scheme must indicate how this is to be done. Furthermore, the equality scheme is to indicate how staff will be trained about equality matters and how the public is to have access to information about the public body's services. To aid public bodies in compiling these equality schemes the Equality Commission has issued guidelines as to the form and content of the schemes.<sup>39</sup>

Certain details must be contained in any equality impact assessment produced by the public body. The EQIA must contain the aims of the policy to which the assessment relates and give details of any consideration given by the authority to -

- (a) measures which might mitigate any adverse impact of that policy on the promotion of equality of opportunity; and
- (b) alternative policies which might better achieve the promotion of equality of opportunity.<sup>40</sup>

More significantly a public body must take the result of an EQIA into account when making any decision about a policy adopted, or proposed to be adopted, by it.<sup>41</sup>

One important way of identifying any adverse impact in the performance of a public body's functions is to analyse any statistical data relating to the performance of them. For example,

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<sup>35</sup> Schedule 9, paragraph 2, Northern Ireland Act 1998.

<sup>36</sup> Schedule 9, Northern Ireland Act 1998.

<sup>37</sup> Schedule 9, paragraph 4(2)(b) and (c), Northern Ireland Act 1998

<sup>38</sup> See paragraph 9.

<sup>39</sup> Schedule 9, paragraph 4(3), Northern Ireland Act 1998. Guide to the Statutory Duties, A Guide to the Implementation of the Statutory Duties on Public Authorities arising from Section 75 of the Northern Ireland Act 1998.

<sup>40</sup> Schedule 9, paragraph 9 (1), Northern Ireland Act 1998.

<sup>41</sup> Schedule 9, paragraph 9 (2), Northern Ireland Act 1998.

significant imbalances in the gender composition of persons availing of a particular service should alert the public body to the possibility that it is delivering the service in a manner which makes it less likely that one gender, rather than the other, can avail of it. The body may therefore have to consider alternative ways of delivering the same service or consider that the unequal take-up of that service can be explained in other grounds. As a consequence, data collection and evaluation are crucial to the effective operation of the section 75 process.

Section 75 clearly has relevance for the delivery of health and personal social services to older persons.

## **5.6 Other human rights obligations**

- **European Social Charter**

The UK is a party to the original European Social Charter of 1961, and though it has signed the revised Charter of 1996, it has not yet ratified it nor has it recognised the collective complaints procedure. Under the ESC process the UK submits annual reports detailing its compliance with the articles of the ESC, though not all articles are examined each year.

A number of the rights in the 1961 Charter are relevant to the topic under review. Article 11 provides a right to individual protection of health, 'enabling him [sic] to enjoy the highest possible standard of health attainable'. Article 13 provides that anyone without adequate resources has the right to social and medical assistance. Paragraph 1 specifies that the person be 'granted adequate assistance and, in the case of sickness, the care necessitated by this condition'. Article 14 complements this by providing that 'everyone has the right to benefit from social welfare services with Article 16, echoing Article 8 of the ECHR, in stating that 'the family as a fundamental unit of society has the right to appropriate social, legal and economic protection'. State parties undertake to create the necessary conditions for the full development of the family 'by such means as social and family benefits, fiscal arrangements, provision of family housing, benefits for the newly married and other appropriate means'.

- **International Covenant on Economic, Social and Cultural Rights**

Relevant articles of the ICESCR are Article 10, 11 and 12 which deal with the family, the right to an adequate standard of living, and the right to health respectively. The salient feature of Article 12 is the 'right of everyone to the enjoyment of the highest standard of physical and mental health. Article 11 recognizes the 'right of everyone to adequate food, clothing and housing and to the continuous improvement of living conditions'. This latter aspect of the Article may have a relevance for older people as they often have a deterioration in their living conditions accordingly as they grow older and encounter financial hardship. The Committee that oversees the Covenant has commented in the past on the issue of 'fuel poverty' and reference is made where appropriate to this.

- **Single Equality Act - Age Discrimination**

The Framework Employment Equality Directive 2000 requires the UK to outlaw age discrimination in the workplace. Consideration may be given to extension the prohibition on age discrimination to others spheres of activity, and a consultation process is to take

place in 2004. Age discrimination legislation that applies to the availability of goods, facilities and services will have implications for the delivery of health and social services. It is too early at this point to determine how extensive the legislation will be. It is likely that age discrimination legislation will be integrated into any future Single Equality Act or Order.

The 2003 report by the Special Rapporteur<sup>42</sup> highlights that discrimination is access to ‘health care and underlying determinants of health as well as means and entitlements for their procurement on the grounds of race, colour... which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health’.

The Committee on Economic, Social and Cultural Rights (CESCR)<sup>43</sup> General Comment 14 (2000) further substantiates the right to the highest attainable standard of health and observes that health facilities, goods and services, including the underlying determinants of health, shall be available, accessible, acceptable and of good quality. The Committee explains each term – for example, ‘accessible’ has four dimensions: accessible without discrimination, physically accessible, economically accessible (*i.e.* affordable), and accessible health-related information.

## 5.7 Summary

The provision of health and social services must increasingly be seen through the prism of human rights and equality law. All citizens have entitlements to such services, and in delivering such services the state is discharging its positive obligations to protect rights to remain free from ill-treatment, to autonomy and personal dignity. The social care sector should not be seen as delivering charity to certain sectors of society, but allowing them to realise their rights. The monitoring of the application of human rights and equality principles can take place through the courts, but also through other, supervisory agencies, like the SSI, by the HPSS authorities themselves, as well as through the international mechanisms. The goal for the future should be to ensure that human rights auditing is mainstreamed into policy design and implementation, in a similar fashion to the way in which Section 75 has resulted in the mainstreaming of equality principles.

## 6.0 Literature Review

The following section within this review focuses on issues that were highlighted as being age discriminatory within the National Services Framework for England and Wales. This literature review particularly focuses on Northern Ireland policies and examines published health research.

When reviewing the plethora of strategy documents relevant to the health care of older people, it is apparent that there is an acceptance of the need to pursue equality and engage in establishing and developing better health services particularly for marginalised groups and those with the greatest needs. The importance of addressing inequalities in health is highlighted in *Investing for Health* (DHSSPS, 2000). Within this document, health is identified as a fundamental human right. As a

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<sup>42</sup> At p 15.

<sup>43</sup> See General Comment 14 (2000).

result, it suggests that DHSSPS must pursue the policies of equity and social inclusion. It aims to tackle the causes of ill-health which are indicated as being social inequalities, social exclusion, discrimination and injustice. The DHSSPS, through New TSN and *Investing for Health*, emphasises the need to move towards targeting of services for those whose health is particularly at risk or those who are excluded and impoverished. Indeed, the document highlights older people as one of its priority groups within the agenda for change, in that; '*as well as extending the length of life we need to improve the quality of those added years*'.<sup>44</sup>

In its document, *Priorities for Action March 2002-2003 and 2003-2004*, the DHSSPS reiterates the need to improve health and reduce inequalities. These documents set out policy aims for the HPSS and identify areas which will be focussed on through New TSN and resource allocation. Goals as set out within the priorities for action since 2002 have focussed on the improvement of services in the following way:

- To improve access and strengthen community services, reducing waiting times for treatment, care, support and minimise unnecessary hospital admissions and facilitate prompt discharge into the community.
- Review the access criteria to domiciliary and home help services and provide further information and advice relating to direct payments scheme.
- Reduce waiting times for those waiting 18 months or more for day case and in patient admissions by 50% (based on June 2002 figures) as a result of measures to improve management of waiting lists. Overall to reduce waiting for in-patient and day case by 5% (based on June 2002 levels).
- Improve assessments giving consideration to rehabilitation potential to ensure inappropriate dependency on more intensive care packages does not develop.
- Implement the recommendation of the Royal Commission on Long Term Care and provide free nursing care to residents.
- The implementation of the SSI Quality Standards for Assessment and Care Planning (1999) which are used in determining care and implement the recommendations of the Valuing Carers Report.
- Implementation of the Carers Strategy and the development of flexible respite services as approved by the minister.
- Improve the effectiveness of HPSS through greater coordination of services across the hospital, community and primary care sectors.

The priorities for action focus on improving and developing services. Continual review of the effectiveness of community care is seen as central to future planning. It is clear that there is now a focus on developing and improving services that have a specific impact on older people. However, these priorities are only aspirations if progress, clear benchmarks and targets are not established to gauge improvements in older people's health care provision. As different policies are implemented by different Trusts, regional benchmarks for the delivery of services are not available. One possible model that might be drawn upon to facilitate a systematic approach to the targeting of services to the elderly is that used in devising Children's Services Plans. The statutory requirement on Boards to establish Committees composed of a wide range of statutory and

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<sup>44</sup> DHSS 2000 p 47.

voluntary sector agencies to devise such plans, on a triennial basis, has provided an impetus on the development of a regional strategy for children services, as can be seen from the recent consultation document, *A Strategy for Children in Need - Developing the Strategy* (August 2003).

There should be a duty imposed on Boards to develop Elderly Services' Plans, paralleling those dealing with Children's Services Plans.

The DHSSPS aims to promote older people's independence, through adequate services, so that residential care is the last resort;

*"Encourage independence, support older people to live in their own homes and communities, promote active participation of older people, recognise rights and values and make public transport more accessible."*<sup>45</sup>

The *National Service Framework for Older People*<sup>46</sup> identifies a number of guiding standards that are pertinent to the delivery of health care in England. Although the Framework is not applicable in Northern Ireland, the guiding standards are worthy of mention because they seek to improve health services delivery specifically to older people. The NHS Framework standards evolved from research into older people's experience of health care throughout the GB professional practice and reviews of policies. At page 6 of the Framework document the following standards are identified as being particularly relevant within this study:

- *The NHS will provide a universal service for all based on clinical need, not ability to pay.* Older people have supported the NHS all their lives. The NHS should be there to provide the services that they need, based on their clinical need alone, and no other consideration (Standard 1).
- *The NHS will provide a comprehensive range of services.* Older people are more likely to have more complex health needs and require access to a full range of primary, community and acute hospital services. They will also benefit from intermediate care initiatives designed to bridge the gap between hospital and home either as part of rehabilitation after an acute event or where a problem can be more appropriately managed by measures other than hospital admission (Standard 3).
- *The NHS will shape its services around the needs and preference of individual patients, their families and their carers.* The NHS is based on a person-centred approach to care (Standard 2).
- *The NHS will respond to different needs of different populations.* Different communities may have different needs; this should be recognised when delivering services to older people from any community. This is particularly important as, in the future there will be a growing number of older people from ethnic communities (Standard 2).
- *The NHS will work together to provide a seamless service for patients.* As people age, they have an increasingly complex range of needs which may mean they need a range of services across health and social services. These should be provided in as "seamless" a

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<sup>45</sup> *Investing For Health 2000.*

<sup>46</sup> DoH 2001.



way as possible, to avoid confusion for older people and their carers and to minimise duplication of effort (Standard 2).

- *The NHS will respect the confidentiality of individual patients and provide open access to information about services, treatment and performance.* Older people should be treated as partners in their own care, and have their confidentiality respected as with other patients. Information should be provided to older people and their carers about the services which are available and the options they have (Standard 2).

*The National Service Framework for Older People, Interim Report on Age Discrimination*<sup>47</sup> details the current findings of the beginning of a process which aims to ‘root out age discrimination’.<sup>48</sup> As an initial step in tackling age discrimination, local HPSS in England began by identifying age discriminatory policies. The long-term aim is to address further less visible age discrimination that results from practice or organisational delivery. The internal audit of age related policies has now taken place.

The NSF Interim Report on Age Discrimination<sup>49</sup> indicates that the fact that the audit was conducted had the added benefit of raising people’s awareness of age discrimination. The audit has shown a very small number of policies that are explicitly discriminatory. These policies are from a wide range of areas as the table below illustrates and it is indicated that there is considerable variation geographically and within regions. With regards to national policies, those that are age-related are considered to be based on good clinical evidence, but the Interim Report indicates the need for a review, at a national level, of these policies in light of equality legislation and human rights.

The audit conducted in England identified 41 specific areas in which age-based policies exist. Although the audit did not take place in Northern Ireland, the areas where age specific policies exist could be reviewed by HPSS in Northern Ireland. The policies identified in the Audit are set out in the table below:

**Table 1:** Written Policies within the NHS with Age-Related Criteria Identified in Audits By Service Area (Excluding areas such as IVF and Child-related services which are seen as irrelevant) (*National Service Framework for Older People Interim Report on Age Discrimination, 2002, p.5*)

<b>Primary Care</b>	<b>Secondary Care</b>	<b>Community Care</b>	<b>Mental Health</b>
Management of coronary heart disease	Resuscitation	Podiatry (+ve)	Mental Health (service organisation)
Hypertension	Hospital admission policies	Continuity care	Liaison psychiatry
Chiropody (+ve)	Access to day surgery	Community rehab teams	Rehabilitation
Audiology (+ve)	Emergency	Older People’s	Clinical

<sup>47</sup> DoH 2002.

<sup>48</sup> See p 2.

<sup>49</sup> DoH 2002.

	Admissions (+ve)	support teams (+ve)	psychology
Gastroenterology screening		Physical Disabilities team	Alcohol dependency
Osteoporosis screening		Community Neuro rehab units	
Over 75 Health Check (+ve)	Older people specialist teams	Health Visiting Community Dietetics	
Flu vaccination (+ve)			
Breast Screening Cervical Screening		Integrated living team therapy (+ve)	
	Adverse clinical incident report	District Nursing (+ve)	
	Pressure sore management(+ve)	Referral to palliative care	
	Transplant policy	Stroke care (rehab)	
Prescribing			
Colorectal cancer screening			
	Anaesthesia guidelines		
	Coronary heart disease		
	Neurology		
	Immediate Stroke Care		

### **(+ve) Examples of positive discrimination (Skewing of resources towards older people)**

Other specific policy areas that the Interim Report highlighted as possibly discriminatory are social care eligibility, funding for residential care, funding levels for home care support, charging policy for domiciliary care, housing policy and access to day care. The report also points to direct age discrimination in areas of health and social care related to the availability of and access to, rehabilitation services, waiting times, hip/knee replacement, cataract removal, coronary artery bypass grafts, misdiagnosis of abuse, resources for drugs, identification and treatment for depression, over-prescribing, access of alcohol and dependency/addiction services, levels of home care available, rates of GP referral and difficulties of older people to travel for hospital services.

The NSF Interim Report indicates that rooting out age discrimination is difficult because of a lack of common definition or wider understanding of age discrimination and the complexity of the issues.

### **Policies in Northern Ireland**

Within this study specific HPSS policies related to the health care provided to respondents have been reviewed. An extensive review of all HPSS policies would have been desirable. However, there are hundreds of policies that are relevant to older peoples' care and treatment, which are

relevant across a spectrum of specialisms and types of care or treatment. Each Health Trust has written policies for individual processes or procedures and within that, each department is responsible for writing and maintaining their policies. In most Trusts policies are held in departments, rather than centrally, and there appears to be no central location where a catalogue of policies is held in each Health Trust.

One of the key stages of the operation of the section 75 process is the screening of policies to assess equality. Some policies are not subject to an EQIA at all, because they are 'screened' out of the section 75 process from the outset, at the point at which the Equality Scheme is devised. Furthermore, within guidance developed by the Equality Commission, it is indicated that when HPSS organisations screen policies to investigate whether an equality impact assessment is necessary, "experience suggests that knowledge is limited" *i.e.* there is an information gap in relation to older people which needs to be filled. Widespread monitoring of service uptake would assist (p.3, Equality Commission, 2003). A thorough review of policies in consultation with older peoples' groups that mention age as a criterion should take place in light of clinical evidence.

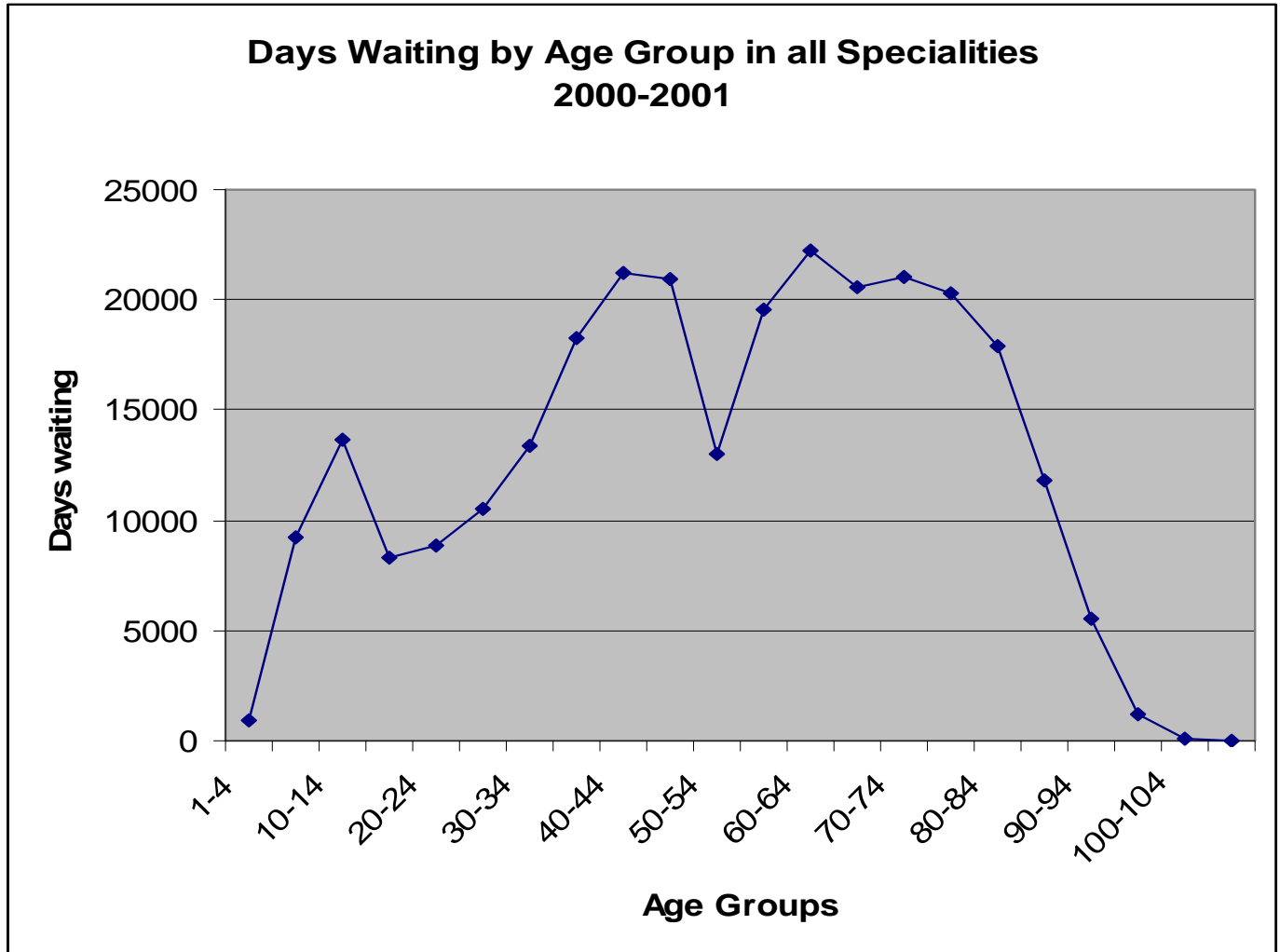
## 6.1 Waiting Lists

Waiting times is an area of health-care which government aims to reduce. Indeed, within the DHSSPS *Priorities for Action 2002-2003 & 2003-2004* it is proposed that waiting times for assessment and access to community care should be reduced. In 2001-2002, eighty-seven per cent of those waiting for a care package were aged over 65. When considering all of those waiting a care package (1,318); 71% waited for domiciliary, 15% for residential and 14% for nursing care) (p.108). Eighty-two per cent of those waiting for community care packages in the year 2001-2002 waited five weeks or more and 60% waited 12 weeks or more (p. 109). In this year, amongst people waiting for care packages for more than five weeks, 85% required domiciliary care and 83% required residential or nursing care. For the year ending March 2002, 8,355 people waited for occupational adaptations. Of those waiting six months or more, 11% were priority cases, 43% were non priority.<sup>50</sup>

In terms of secondary care, DHSSPS sets as one of its priorities the improvement of the responsiveness of hospital services to demand. The following graph illustrates how hospital services are responding to demand, by illustrating those waiting by age group, in all specialities 2001-2002.

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<sup>50</sup> McWhirter 2002 pp 108-109. Figures are for the year March 2001-2002.



Source: DHSSPS, Days waiting for all specialisms within age groups for 2001/2002  
 The above graph illustrates that those aged 60-64 years wait longer than any other age group and the general trend indicates that waiting times are long between the ages of 60-64 to 80-84.

The table below illustrates the upper quartile (*i.e.* the top 25%) of those specialisms that had the highest average number of days of completed waits (*i.e.* those waits that have been completed either by death or discharge) in 2001/2002:

**Mean Wait Duration in Days for Deaths and Discharges of the Top 25% (with the longest waiting times); specialisms by three Age Bands for Year 2001-2002**

Specialty Code	0 - 29	30 - 59	60+	TOTAL
Thoracic Surgery	266	212	119	597
Dermatology	293	165	185	643
General Surgery	193	408	330	931
Oral Surgery	318	316	327	961

<b>Gastroenterology</b>	208	430	527	1165
<b>Gynaecology</b>	192	492	540	1224
<b>T&amp;O</b>	254	546	520	1320
<b>Pain Management</b>	191	688	699	1578
<b>Plastic Surgery</b>	829	483	359	1672
<b>ENT</b>	946	724	237	1908
<b>Urology</b>	836	527	610	1973
<b>Cardiac Surgery</b>	702	708	585	1996
<b>Ophthalmology</b>	771	510	1191	2473

\*Source: Hospital Inpatients Systems (Statistics and Research Branch, DHSSPS)

It is apparent that older people are particularly heavier users of many of these specialisms with the longest waiting times. For instance those patients waiting for Ophthalmology had the highest number of days waiting (2,473 days) with those over 60 waiting the longest (1,191 days). However, other specialisms also have high mean waiting times for those in the other age bands. Even though those over 60 years of age do not necessarily have the highest mean waiting times for all of the above specialisms; many older people tend to rely heavily on these.

## 6.2 Carers

There are about 250,000 carers in Northern Ireland with 18% of all households containing a carer. The *Informal Carers Report* (DHSSPS, 2001) outlines information gathered as part of a survey for the *Health and Social Well Being Survey*.<sup>51</sup> The survey highlights that 9 out of 10 carers were looking after someone who was related to them, 46% were looking after a parent, 22% care for a spouse or partner and 16% for a child.

Almost two-thirds of dependents were aged 65 and more than two-thirds of them are women. Forty-two per cent of dependents who live in the same household as their carers were aged 65 or over. More than three-quarters of dependents, who do not live with their carer, are aged 65 or over thus highlighting older people's level of dependency on informal carers coming into their homes to assist them.

Amongst carers who do not live in the same household as their dependent, 14% spent more than 20 hours per week caring. The type of assistance given is as follows: shopping (82%), keeping company (77%), keeping an eye on (66%) and taking out (62%). Amongst those who did live with their dependent, the type of care given included physical help (72%), personal care (70%) and giving medicines (59%).

It was apparent from the survey that carers had higher levels of longstanding illnesses, which included stress, and a higher proportion, as compared to non carers, showed signs of psychiatric morbidity and heavier levels of smoking.

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<sup>51</sup> DHSS 1997.

In Great Britain the Carers (Recognition of Services) Act 1995 identified carers as having their own needs. The Carers and Direct Payments Act (NI) 2002 now makes provision, in Northern Ireland, for carers to be assessed for community care assistance even when their dependent refuses an assessment of their own. The Act also indicates that Social Services have the ability to be innovative and creative in providing carers' services. The Act provides for the direct payment to carers or the development of voucher schemes to promote greater flexibility for carers and those cared for. The Act requires Trusts to carry out carers' assessments and establish the level of assistance required if the carer requests an assessment.

Following consultation, the DHSSPS published a study report, *Valuing Carers, Proposal for a Strategy for Carers in Northern Ireland (2002)*. The report indicated that more funding is required for the provision of support so that the role and quality of caring is enhanced. It suggested that carers should be fully informed and involved in the planning of care and it recommends that carers are identified in a discharge letters to GPs. Developing signposting to information, advice and support networks was also seen of paramount importance and the new Local Social and Health Care Groups were to act upon this request. Also, complaints procedures were to be uncomplicated and supportive of carers.

In this study carers were asked about their experiences of the health-care system and services that they have received. It is evident that services were not as responsive as implied by policy documents. Carers indicated that they had to 'fight their corner' to receive equipment or extra assistance to help them care.

### **6.3 Accessing Services and Information**

Within the recent report, *Barrier to Essential Services (OFMDFM, 2001)*, issues such as income level and fear of using new technology were seen as important elements in preventing older people from accessing health care services and information. The ability to travel is fundamental to older people in accessing care. There are problems with public transport, for instance there is a lack of bus routes, which are in walking distance of those with mobility problems. Furthermore, the travel costs for those living in rural areas are higher, due to reduced access to public transport.

Perceptions of older people when requesting services are also highlighted as a barrier. Older people suggested that they often felt discouraged when attempting to access services, because they felt that they are a lower priority in comparison to younger people<sup>52</sup> and health information provision also appears to be limited. Research has also shown that higher proportions of older people were not offered health and lifestyle advice although many older people are unaware that their lifestyles are unhealthy.<sup>53</sup>

The problems arising from a lack of information and easily accessible transport were raised when conducting interviews with older people in this study. For instance, it was found that an older person in this study walked from the bus station to a hospital rather than avail of the free bus. She was unaware of the service. Another respondent, who lived on her own in a town, used a taxi to attend her hospital appointments rather than a bus because she could not walk to the bus stop.

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<sup>52</sup> Dunn & Morgan 2001.

<sup>53</sup> Little 1999.

Furthermore, when discussing the delivery of social care and entitlements, older people in this study were unclear about policy as it differed between Trusts. In terms of accessing information, no one organisation is responsible for the delivery of accurate and relevant health information and services to older people.

## 6.4 Screening

As already indicated, screening policies in England and Wales have been identified as including age explicit barriers to older people. When examining the breast screening policy in the past it has only been offered to women aged between 50 and 64 every three years. There are current plans and funding set aside within the DHSSPS to extend this screening programme to those aged up to 70 years.

If, for instance, a Breast Screening Programme is adopted as suggested, that introduces an upper age limit, unless it is based on clinical evidence, it could result in double discrimination, of older women.

Yet, research shows that older women over the age of 64 years would take up the opportunity<sup>54</sup> indeed, predictors of non-uptake include socio-economic factors and general health.<sup>55</sup> A new general medical screening contract has no provision to continue with the general screening medical for those over 75.

Those devising screening policies should be aware of the impact of their decisions in light of human rights and equality legislation. Policies which discriminate on the grounds of age involve prima facie cases of discrimination under the HRA and section 75. However, such policies may be permissible if they can be objectively justified, preferably on the basis of empirical evidence, and amount to 'proportionate' manner of achieving a legitimate aim. Under section 75, a HPSS authority may need to assess methods of alleviating the adverse impact of the policy on other groups.

## 6.5 Treatment

### *Cancer*

The proportion of the United Kingdom population over 75 years of age will increase from around 7% to nearly 11% in the next 50 years, with a disproportionate rise in those aged over 85 years<sup>56</sup> and there will be a large increase in the number of older patients with cancer; already over one third of cancers are diagnosed in people over 75. Yet there is evidence of clinical trials using arbitrary upper age limits. Very few studies include large numbers of people aged over 75 or over 85. The role and effectiveness of many cancer treatments is therefore not evidence-based on those most affected. A review was conducted in 2003<sup>57</sup> of the Yorkshire Cancer Register which covers 3.7 million people with cancer, constituting 7.2% of the population in England and Wales. The results highlighted that even though one third of cancers are diagnosed in people aged over 75, it

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<sup>54</sup> Edwards and Janes 2000.

<sup>55</sup> Harris *et al* 2002

<sup>56</sup> Turner *et al* 1999.

<sup>57</sup> Turner 2003.

was proposed that this group was less extensively investigated and received less treatment than younger patients. The authors indicated that reduced levels of intervention are not wholly explained by appropriate adjustment for co-morbidity or frailty.

Surgery is performed less often in older patients with non-small cell lung cancer, despite tumours such as these being operable.<sup>58</sup> This surgery can be performed safely in older patients selected according to the same anatomical and physiological criteria used in younger subjects.<sup>59</sup> Operative risks increases with age, but with modern anaesthetic and surgical techniques this can be reduced to acceptable levels, even in the oldest age groups.<sup>60</sup>

Older women with ovarian cancer, in whom optimal “debulking” of the tumour offers improved survival rates, are also indicated as being much less likely to have surgery.<sup>61</sup> The reasons for this have not been uncovered. In breast cancer too, reduced use of surgery (no operation or less extensive procedures) correlates with advancing age. Researchers indicate that there is a trend for less breast conserving surgery and fewer reconstruction procedures, perhaps based on the questionable belief that older women do not have the same concerns about body image.<sup>62</sup> Furthermore Farrow *et al* (1996) indicated that there is an increase in surgical treatment and survival of older patients in recent years. In terms of treatment of older people, this research highlights that older patients can tolerate some chemotherapy regimens, even at full dose. In their analysis Turner *et al* (2003) highlighted that radiotherapy is used less often in older patients, although its safe use, without increased toxicity, has been described in this population. This includes radical radiotherapy in pelvic malignancies and radiotherapy of curative intent in thoracic cancers.<sup>63</sup> Older patients receive more palliative than curative radiotherapy, but decisions on treatment protocols are not influenced by chronological age once the patient has been referred to a radiotherapist.<sup>64</sup>

In summary Turner *et al* (2003) indicate that cancer in old age is not managed the same way as in younger people, and the differences are not wholly explained by appropriate adjustment for the condition of the individual patients. As yet, the variables, which predominantly influence decision-making, are unknown.<sup>65</sup> The following questions are raised:

- Is it the patient’s or the family’s acceptance of therapy or the physician’s opinions, which affect choices (including possible bias based on chronological rather than biological age alone)?
- Is it possible that healthcare professionals are delivering a poor standard of care to some older cancer patients?

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<sup>58</sup> Guadagnoli *et al* 1990.

<sup>59</sup> Morandi *et al* 1997.

<sup>60</sup> Bufalari *et al* 1996.

<sup>61</sup> Ries 1997.

<sup>62</sup> Busch 1996.

<sup>63</sup> Pignon *et al* 1998 and 1997.

<sup>64</sup> Shank *et al* 1992.

<sup>65</sup> Fentiment 1996.



Where an older person dies as a result of the refusal to administer certain treatment, or his or her death is hastened by such a decision, the state's positive obligations under Article 2, the right to life, are engaged. As discussed above, the state's obligations in this regard are not absolute, but some consideration must be given to the reasons for a HPSS authority's actions or inactivity as the case may be.

Understanding which criteria are used in making decisions is seen as crucial in determining if older people are being disadvantaged. It will be necessary that patients' and doctors' knowledge about effective and acceptable investigations and cancer treatments should be identified. Also, Turner *et al* (2003) indicate that there is a need to scrutinise the best way to manage common cancers in old age, especially breast, colorectal, lung, and prostate cancers which should include data on any impairments experienced by the individual, health related quality of life and psychological well being as well as physical outcome measures.

## **6.6 Pain Management**

Specific research has indicated mistreatment of older people. For instance, Cowan *et al* (2003) highlighted that pain management within care homes is a 'neglected problem'. The authors point to inadequate assessment and treatment of pain among older people. Cowan *et al* indicate that because older people, particularly within care homes may have cognitive impairments, inadequate assessment by healthcare professionals may result.

This links with other research that shows that in cancer care, increasing age is an independent predictor of inadequate pain management.<sup>66</sup> For example, fear of addiction to opiates, the belief that "good" patients do not complain of pain, and concern that treatment of pain will distract effort from treating the cancer are examples of patient related barriers to the management of cancer pain: older patients are more likely to have these concerns.<sup>67</sup> Also, family caregivers may have similar concerns, and their views can influence successful pain control. Cowan *et al* (2003) indicate that cognitively impaired older patients may under-report pain, but their complaints of pain are no less valid than those of cognitively intact individuals. This research also suggests a need for improved education of pain management for older people.

## **6.7 A&E**

There is evidence to suggest that medical staff in A&E do not always recognise the life-threatening nature of apparently 'moderate' injuries in older patients and older patients are much less likely than younger patients with similar injuries to receive appropriate treatment, for example intensive care or referral for specialist investigation.<sup>68</sup>

## **6.8 Care, Respect and Discrimination**

The dignity and autonomy of people although inter-related are two different concepts. Dignity refers to an individual maintaining self respect and being valued by others. Autonomy refers to

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<sup>66</sup> Turner *et al* 2003.

<sup>67</sup> As above.

<sup>68</sup> Grant *et al* 2000.

individual control of decision-making and other activities. Dignity is challenged primarily through negative interactions between staff and patients, a lack of regard for patients' privacy, and a general insensitivity to the needs and desires of an older population (Age Concern, 1999). Autonomy is threatened when patients (and their carers) are not given adequate information or the opportunity to understand fully their diagnosis and to make informed choices about their care.

Investigations into acute hospital care in Britain in the 1990s found evidence of inadequate treatment. Some hospitals were failing to meet basic standards of nutrition and personal hygiene for older patients (HAS, 2000). It is suggested that since the investigation by the Health Advisory Service (HAS) little has changed, as identified by National Standing Nursing and Midwifery Advisory Committee (2001). Lack of resources has been suggested as the cause of a drop in standards. However, a report published by Help the Aged (*Dignity on the Ward*) states that the cause is rooted in the culture of care for older people and that the attitude of many staff towards older people was very negative. This in turn has meant that older people's expectations of the service were low.<sup>69</sup>

In Northern Ireland, increased turnover of patients per bed has led to 'inefficiencies': "*Overall current services are operating at very high levels of activity, with capacity shortages in some areas leading to inefficiencies, related to too intensive use of the available facilities*".<sup>70</sup> This signals possible problems with the quality of standards. A recent report conducted in Northern Ireland<sup>71</sup> on the quality of care received by older people in hospital highlights inadequacies in care provided. The report highlights the need to address waiting times following emergency admissions of older people to hospital for surgery and for emergency hip replacements. Older people experienced negative and disrespectful attitudes from health service staff.

In this study, older people highlighted, through interviews, incidences whereby their dignity and autonomy have been compromised in health care settings. Older people indicated that they at times felt ignored or treated in an infantile manner. For example, an older man was discharged and placed into a home specifically for people with dementia. In this case, the discharge plans were not discussed and he received limited information in terms of where he was going and when.

A survey of nurses and students working with older people in the clinical setting concluded that the sample "expressed stereotypical views about old people in general".<sup>72</sup> Such findings are supported by the report by the UK Health Advisory Service: "We did encounter examples of prejudiced attitudes towards older people and their care at almost every level of the service system"<sup>73</sup> Researchers conducting literature reviews have reached similar conclusions.<sup>74</sup>

Discriminatory attitudes may include the following;

- Perceptions of older people having had a 'fair innings' and therefore being less deserving of limited health and social care resources.

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<sup>69</sup> Lothian & Phillip 2001.

<sup>70</sup> McWhirter 2002 p110.

<sup>71</sup> EHSSC 2003.

<sup>72</sup> Keelson *et al* 1998.

<sup>73</sup> HAS 2000.

<sup>74</sup> Bernard 1998.

- Younger health service professionals not valuing older people's quality of life.
- Older people viewed as dependent and resource draining because of their economic inactivity.

Health aspects of the older population may be characterised as normal aspects of ageing. Low expectations of what can be achieved for older people in acute and community health and social care settings are self-fulfilling on behalf of commissioners and providers. Low expectations of older people's mental capacity produce inappropriate and infantilising behaviours. Negative attitudes of staff have been suggested as affecting the quality of care.<sup>75</sup>

With reference to racial discrimination the *Race Equality and Health, a Good Practice Guide Consultation Document, Equality Commission and DHSSPS (2002)* suggests that there is evidence of racial discrimination within the delivery of health services. Some of the barriers highlighted were the following:

- Language and communication barriers
- Lack of access to appropriate information
- Lack of culturally sensitive services related to religious or cultural needs.
- Institutional racism
- Different health belief systems and procedures
- Negative previous experiences of the health service
- Attitudes of some health staff
- Fears about entitlement to health care
- Immigration restrictions and confusion

The good practice guide states that:

*“The cumulative effect of all these factors, many... hidden ... Providers should avoid a colour-blind approach, which attempts to operate an open door policy offering one standard of service for everyone... Recognising that a patient from a black or ethnic background may have different needs and face different problems from white, settled patient is not discriminatory. However, providing the same service in the face of differing need may be.”*

Provisions, criteria or practices that are applied equally to all may amount to indirect discrimination. The new, European Union law, definition of this concept provides that discrimination arises because the provision, criterion or practice puts persons of the same age as the complainant, as well as the complainant, at a particular disadvantage when compared to persons of different ages. The alleged discriminator can defend the case if he or she can show that in imposing this provision, criterion or practice, he or she is pursuing a legitimate aim in a proportionate manner. This will require the alleged discriminator to show that there is a genuine, supportable purpose for having the provision, criterion or practice and that the manner in which that purpose is being pursued is reasonable. The Framework Employment Equality Directive 2000, as stated earlier, only requires the UK to introduce anti age discrimination legislation in respect of employment, but the process of enacting the Single Equality Act may result in legislative protection in other areas of activity, including goods, facilities and services. In any

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<sup>75</sup> HAS 2000.

event, the existing anti-racism legislation, the Race Relation (Northern Ireland) Order 1997,<sup>76</sup> may be invoked to challenge racism in the delivery of health and personal social services.

The Race Equality Guide requests that there is clear guidance to staff, that patients should be able to communicate with all health workers and services and those services should be readily accessed via clear signposting and information provided in the respective languages.

## **6.9 Referrals**

Lothian and Philip (2001) indicate that there is reduced referral to specialists with increasing age, though the rationale behind this is not clear and that doctors are poor at judging the health related quality of life of their older patients. Older people may be more likely to follow their doctor's recommendations without question, but the way in which treatment options are presented can influence their choice. Lack of knowledge about the ageing process among doctors may also be a problem. Some may be unaware that a 75-year-old woman has a life expectancy of 11.1 years and that of a 75 year old man 8.5 years. To help overcome this, Lothian and Philip (2001) highlight that there has been a move in the United States to integrate geriatric medicine into the subspecialties of medicine, particularly oncology.

## **6.10 Choices, Consent and Do Not Resuscitate (DNR)**

Following the controversial findings of a report in [year] published by Age Concern relating to DNR orders on older people's medical notes, debate has intensified. Families have indicated that decisions have and are being taken not to resuscitate their family members without discussion.

Reviews of decisions not to resuscitate have indicated that patients poorly understand them, information given is not recalled, and viewpoints may change.<sup>77</sup> It has been indicated that there is room within current consent guidelines for great manipulation of decisions.<sup>78</sup> It is possible that, in future, patients who have been denied treatments, causing them to die, or to suffer degrading treatment above the minimum threshold necessary to engage Convention right Article 3, may invoke either Article 2 or Article 3, depending on the outcome of the refusal to provide treatment. Much will of course depend on the judiciary's assessment of what the State needs to do to satisfy its positive obligations.

Advice from medical professional bodies, such as the Royal College of Physicians in 1991 indicates that chronological age is not as important as disease severity and co-morbidity in determining ability to benefit from treatment.

The need for ascertaining and taking into account people's views about their care and treatment is seen as an important part of building "ethics of evidence" a more rounded body of knowledge on the appropriateness of planned care or treatment.<sup>79</sup> There is a suggestion that at times patients and

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<sup>76</sup> And the amending Race Relations Order (Amendment) Regulations (Northern Ireland) 2003.

<sup>77</sup> Levin *et al* & Sayers 1997.

<sup>78</sup> Edwards & Elwyn 2001.

<sup>79</sup> Bowling & Ebrahim 2001.

in particular older patients do not want to be involved in clinical decisions about their treatment. Should this prevent health professionals offering older people choices about their treatment?

The under-representation of older people in clinical trials<sup>80</sup> and the evidence that clinical judgments may be influenced by the socio-demographic characteristics of the patient (including age), stereotyping, as well as healthcare resource constraints and prioritization of services point to older people not being treated fairly or equally.<sup>81</sup> Bowling (2001) suggests that in general most doctors choose treatments that are most likely to maximise life expectancy; however in the case of older people it is presumed that older patients will prefer to maximise their quality of life at the expense of quantity.

The aforementioned research also called for patients to be informed about the range of cost effective treatment options appropriate for their condition and an understanding of their preferences which is an integral part of enhancing the quality of health care received. Currently, consent guidelines indicate that patients should be given options and choices should be offered. Decisions should be made jointly and all choices should be provided with appropriate clinical guidance.<sup>82</sup> Any divergence from obtaining consent or forcing older people to have treatment against their will could be construed as mistreatment or abuse and therefore a breach of Article 3 HRA. As indicated earlier in this report highlights individuals should be free from non-consensual medical treatment (see page 15).

In this study, an older person highlighted that she felt coerced into receiving an examination of her oesophagus. This individual indicated that the information and reasons for the procedure were not adequately explained. It is apparent in her account that the decision to carry out the examination was not a joint one.

## 6.11 Hospital Discharge

Within the Review of Community Care, the Project Board acknowledged claims that service users were discharged '*quicker and sicker*'.<sup>83</sup> than in the past. This has meant that there is increasing pressure on community resources to treat and care for patients.

By 31 March 2002, there were 375 patients in acute hospitals that were delayed discharges. They required nursing packages (54%), residential care (13%) and domiciliary care packages (33%). The vast majority of these cares were older people (93%) and 81% were over 75 years of age. 35% of the delayed discharge cases were attributable to no funding being available. Fifty-four per cent were delayed discharges by one month, 26% by two months and 13% at least three months. Nursing home care packages tended to have longer delays and those awaiting residential places shorter delays (but only slightly).<sup>84</sup>

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<sup>80</sup> Bugeja *et al* 1997.

<sup>81</sup> Bowling 1999.

<sup>82</sup> DHSSPS 2003.

<sup>83</sup> DHSSPS 2002 p. 7.

<sup>84</sup> McWhirter 2002.

Patients' rights may be infringed by delays if they are unable to return home because of insufficient community services and if they prefer to be at home. The Review of Community Care recommended a number of ways in which discharges from hospital could be improved:

- Common discharge planning policy and procedures.
- Review and update of discharge policies and procedures
- Increase face-to-face contact between staff in trusts and community services
- Interface with hospital
- Making permanent decisions about a person's future care in acute hospitals should be avoided.
- Hospital staff should have budgets for services for people with less complex needs, such as home help, so that patients are not unduly delayed.
- Improved communication should be developed between GP's and hospital consultants
- Focus on extent of inappropriate hospital admission and the development of suitable preventative strategies.
- Increased use of pre-admission screening and assessment for services users facing elective surgery.

Within the Review of Community care it was recommended that Health Trusts should revisit the 1997 SSI (Social Services Inspectorate) Report, *From Hospital to Home* to ensure that the recommendations within this report have been given due consideration in their Trust area.

Within policy the seamless discharge of people from hospital to home is strived for. However, within this research, an older person highlights how he was temporarily displaced from going home because of deficiencies within services. This set of facts engages Article 8, a person's right to respect of home and family life, and a HPSS authority will be required to justify any interference with the right.

## **6.12 Assessment of Need**

Quality Standards have been established by the Social Services Inspectorate (*Quality Standards, Assessment and Care Management*) regarding care assessments. Within the Review of Community Care, the Project Board requests that Trusts revisit these standards.

Each Health Trust has a set of procedures for negotiating with users and carers the most appropriate way of creating and implementing a plan to achieve the objectives identified by assessment. There is no Northern Ireland-wide *pro forma* and each health trust uses different assessment methods. Health trusts view flexibility within the provision of services as being useful so that they can respond to local need. Assessment and corresponding plans are aimed to remain flexible so that resources can be used in a creative way so as to respond to users' needs.

Each Health trust is responsible for responding and developing effective and appropriate assessment procedures. It is their aim to deliver the most suitable services according to need; however, the Review of Community Care (2002) indicates that:

‘... *There is a trend to rely on nursing home provision rather than domiciliary care*’ and that delivery ‘*was service led rather than person centred.*’<sup>85</sup>

Within this research, older people very often felt that care plans are more responsive to service constraints rather than health needs. For instance throughout the detailing of older people’s experience of the health care system in relation to unmet need, discharge and planning of services, rehabilitation services, the provision of home-helps resource constraint determined at times, whether they remained in their own home and their perception of their quality of life.

### **6.13 Domiciliary, Residential and Nursing Home Care**

#### Domiciliary Care

Of the 27,041 people in receipt of Home Help service at 31 March 2001, 40% were provided for by Homefirst Community HSST, South and East Belfast HSST and North and West Belfast HSST. The majority of people receiving home help were in the 75-84 age-group. The number of people receiving home help has increased slightly over three years per head of population aged 75 and over; however, there has been a decrease of 5% in the number of older people (aged 65 and over) receiving home help since 1996.<sup>86</sup> There has been a decrease in the number of people per 1,000 population aged 65 and over registered in day care from 14.4% (1990/00) to 13.2% (2000/2001). Between 1997/1998 and 1999/2000 the per capita expenditure per person increased from £1,017 to £1,201.

Within the Review of Community Care referred to above, it was indicated that older people preferred to live in their own homes for as long as possible. As part of this study, older people expressed that they would prefer domiciliary care, in trying to remain in their own homes rather than nursing home care. HPSS authorities’ positive obligation to ensure that rights-holders can exercise their Article 8 rights would mean that those authorities would have to consider whether it would be possible for an older person to live on in his or her own home, if that was the elderly person's wish, and to justify any decision not to support such a desire.

### **6.14 Prescribing for Older People**

Within the Review of Community Care (2002) adverse reactions to drugs were implicated in 3% to 17% of hospital admissions, costing the health service well in excess of £13 million annually. Enhancing the role of community pharmacists in primary care and community care systems is proposed by the Community Care Project Group as a way to alleviate this problem and ensure that people are being prescribed for appropriately. Further suggestions to ensure safe use of medicine include that medication is brought to the attention of all community staff, medicines review becomes a routine part of the care review process and education and training is given to carers in the safe use and administration of medicine; this is also highlighted within the *Valuing Carers, Proposal for a Strategy for Carers in Northern Ireland.*<sup>87</sup>

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<sup>85</sup> DHSSPS 2002 p. 35.

<sup>86</sup> DHSSPS 2002.

<sup>87</sup> DHSSPS 2002.

The problems associated with the administration and prescription of drugs was highlighted in a study commissioned by the Northern Health & Social Services Board in 1998. The Project reviewed the scale of pharmaceutical care issues occurring with housebound patients. GPs from 5 practices enrolled 36 patients, 21 who had the inclusion criteria. The problems with their medication included: compliance problems (52%), medication not synchronised (52%), inappropriate medication (38%), incorrect dosage (24%), adverse drug reaction (24%) and unable to open CRC (Child Resistant Caps) (24%) (Review of Community Care, 2002). ‘Polypharmacy’ is claimed to be the norm and not the exception within the older population, resulting from a lack of medication review, inappropriate prescribing and emphasis on preventative treatments. Many of the prescriptions received by older people are repeat and not following a consultation with their doctors. Studies in the UK have highlighted that inappropriate drug prescribing for older people is common in general practice.<sup>88</sup>

Further to this, institutionalized patients (for examples those living in nursing homes) are viewed to be on even a greater number of drugs than those who may have similar ailments but who live in their own homes. It is claimed that because older people see different doctors, drugs are prescribed without adequate patient review.<sup>89</sup>

The use of dosettes (monitored dosage systems) assists older people and their carers to comply with medicines treatment regimes. At present the use of dosettes (such as Manderex or Nomad) are not subsidized by the NHS and older people often have to pay for this service every time they require medication (this can be up to £3). Subsidisation of dosettes could prevent hospital admissions as a result of inappropriate prescribing or drug reactions.<sup>90</sup>

When discussing medication with an older person in this study, it was apparent that medicines were not reviewed systematically (See p. 56).

## 6.15 Cardiology

Professor Bowling (1999) in her article ‘Ageism in Cardiology’ points out that there is evidence that higher rates of lifesaving and life enhancing cardiology interventions occur among younger people than among older people. Older people and older women in particular, she suggests, are less likely to receive appropriate cardiology investigations from echocardiography to measuring cholesterol concentrations.

Stone (1996) indicates that whilst older people are more likely to have more severe disease they are treated medically rather than surgically and are less likely to receive the most effective treatment after acute myocardial infarction.<sup>91</sup> Bowling also indicates that they receive thrombolytic treatment less often than younger people, even in the absence of contraindications. The effects of age on access to health care occur independently of sex and it is further suggested by Bowling that age based rationing of treatment is defended on the grounds that older people have had “fair

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<sup>88</sup> Lindley *et al* 1992; Buetow *et al* 1996.

<sup>89</sup> National Medicines Information Centre 2000.

<sup>90</sup> Thomas & Brennan 2000.

<sup>91</sup> McLaughlin *et al* 1996 and Wegner 1997.



innings”.<sup>92</sup> Yet, clinical delay or denying older people the benefit of certain interventions may lead to greater spending on "maintenance" services such as those provided by district nurses, home helps, and "meals on wheels" programmes. Indeed, the provision of more invasive treatments could be cost effective in enabling people to function independently. Bowling suggests that clinical guidelines should be developed and regularly updated to enable clinicians to make more informed decisions about treating older people, and access to investigations and treatments should be monitored centrally. She also indicates that hospital league tables of intervention rates by the age and sex of the patient and standardised for the age and sex distribution in the population could be published. It is suggested that ageism as it exists in clinical medicine and health policy reflects ageism in wider society and thus Professor Bowling calls for the general empowerment of older people so that they can influence care and treatment offered when requiring treatment, particularly in the field of cardiology.

### **6.16 Exclusion in Research**

Bayer and Tadd (2000) reviewed studies submitted for ethical approval to Bro Taf (a medical ethical group) in the first seven months of 1999 to determine whether upper age limits were justified. Of the 155 studies that were of relevance to older people, over half had an upper age limit that was unjustified and neither the local ethics committee nor the multi-centre research ethics committee had requested justification for the age restrictions.

Negative stereotyping of older people was reflected in comments in the studies that participants need to be “fully competent”, “reliable”, or “without cognitive impairment”. One argument for an upper age limit is that it minimises the rate of dropout. However, Bayer and Tadd (2000) stress that there is no evidence to suggest that older people are less compliant with the demands of research protocols and indicate that older peoples’ participation may be much easier because of their fewer family and employment commitments.

The exclusion of older people has also an impact on the generalise-ability of study findings. If researchers can be certain that older people will not respond differently from other age groups within clinical trails, their specific inclusion may not be an issue. However, as indicated by the European Commission Committee on Proprietary Medicinal Products, if this is not the case, their inclusion is essential.

Bugeja *et al* (1997) also found exclusion of older people from clinical trials when reviewing published reports. They propose that clinical trials are stratified in terms of age so as to insure that an appropriate proportion of older people are included to reflect the wider population. They are, therefore, significantly underrepresented in the evidence base used to determine clinical effectiveness<sup>93</sup> and as a result clinicians are then cautious when treating older patients with more recent drugs.

Ethics committees are in a strong position to influence research practice and to reduce unethical age discrimination and it has been suggested that they should request justification whenever protocols include inappropriate age restrictions and if this is not forthcoming, approval might be

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<sup>92</sup> Williams 1997.

<sup>93</sup> McMehan & Adgey 1998.

conditional on age limits being removed.<sup>94</sup> Bowling (1999) calls for research organisations encouraging those who design clinical trials to include large numbers of older people in an effort to redress the balance of evidence of clinical outcomes.

As a result of proposed changes it is anticipated that more positive attitudes towards older people among researchers would result as well as safer, more effective treatments and services. On a more practical note, given the importance of public authorities in having regard to the need to promote equality of opportunity under Section 75, research on older people would prove valuable in assessing whether adverse impacts existed.

## **6.17 Summary**

The review of clinically based research of specific health care areas has indicated that older people in these studies have been discriminated against, by the withholding of treatment on the basis of age. This applies to areas such as the type of cancer treatment recommended, screening, the type of cardiological intervention and referrals as well as the failure in homes to appropriately administer medicines and the aggressive, racial, or ageist attitudes of HPSS staff. Delayed discharges could be construed as a breach of Article 8 if the delay was unjustifiable when considering public authorities resource constraints.

The following section examines the experiences of older people in Northern Ireland of the health care system and indicates potential breaches of human rights.

## **7.0 Interviews Analysis and Policy Review**

Generally, older people are not aware that services were not delivered or offered to them because of their age. However, racial discrimination, disrespectful treatment and unmet needs were issues raised by respondents. Those who advised this report that they had been disrespectfully treated did not perceive that they were treated this way specifically because of their age.

As the focus within this study was to outline unmet need, inequalities, double or multiple discrimination, etc, the accounts detailed below do not include citations of many older people who praised their GP's, Consultants, Nurses and Carers whom they felt surpassed their duties and were excellent in providing care and assistance. The following sections detail the specific issues highlighted within the interviews and examine them in light of human rights legislation and policies prescribed by Trusts and DHSSPS.

### **7.1 Racial Discrimination**

Older people from the Chinese community in particular, highlighted the difficulties that they faced when trying to communicate with health professionals. Those interviewed from the Indian community were bilingual and had no problems, either in the past or present, in accessing health care. However, the group of older Chinese people approached in this study could speak very little

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<sup>94</sup> Bugeja *et al* 1997.

English even though they have lived in Northern Ireland for some time. The development worker for the community suggested that illiteracy levels are high – about 75 to 90% of older Chinese people cannot read or write Chinese and about 90% cannot read, write or speak English.

The language barriers and the problems it causes are highlighted by the following account given by a local community worker:

*“About last year we had a serious incident where an elderly Chinese gentleman took ill. They called an ambulance, but couldn’t communicate with him; all they knew was that he had a pain in his stomach. It was severe and it was distressing for the man and those trying to assist him. He was lying there clutching his stomach and no-one knew what was wrong.”*

When speaking to a Chinese couple with the help of an interpreter, the following Chinese man spoke of how they were treated. He suggested that they were treated as if they were stupid by health care workers because they cannot understand English:

*“If you cannot answer you are dumb, you cannot speak because you can’t speak English”.*

He said that going to the GP to explain what is wrong is difficult. They can barely do it properly because there is no proper communication as there is no interpreter. As a result they feel that they are treated as ‘trouble’:

*“We are more trouble because we can’t speak English”*

“Is that the way you feel?”

“Yes.”

“What about drugs medication?”

*“They find it difficult to understand what drugs are for because they find it difficult to understand their doctor.”*

The language barriers are accentuated for Chinese older people because of vulnerability; this constitutes double discrimination. As a result they have little understanding of their entitlements and find it very difficult to relay their needs. The Equality Commission Northern Ireland and the DHSSPS have produced a ‘Racial Equality Good Practice Guide’ which states that *‘failing to provide interpreting facilities in relation to service provision, when it is known that there is a language barrier could be construed as unlawful discrimination’*. In an effort to address the needs of ethnic groups, the Eastern Health and Social Services Board have funded Chinese Community interpreters. However, evidence from service users indicates that the provision of interpreters and translated materials remains the exception rather than the norm (Holder & Lanao, 2001:8).

In a recent report completed by the Multi-Cultural Resource Centre NI,<sup>95</sup> the standards of English among those Chinese surveyed appear to be high in Northern Ireland. For instance, 61% have

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<sup>95</sup> MCRC, Holder 2000.

basic written English, 28% have intermediate and 11% were deemed proficient. With regards to spoken English, 58% had basic spoken English, 25% intermediate and 17% proficient. However, these figures were not reviewed in terms of age groups. Overall, even though the findings recorded relatively high levels of spoken English, 62% of those surveyed indicated that they required an interpreter when visiting a doctor and only 1.2% have said that they have had the opportunity to avail of this service. Holder (2003) indicates that there are '*pockets of good practice*' but adds that there is a need to extend these practises relating to the provision of information in respective languages and the provision of interpreting services.

Further to the language barriers and access to appropriate information, the Equality Commission (ECNI) and DHSSPS, *Consultation Good Practice Guide, Racial Equality in Health* also highlighted further issues that needed to be addressed by HPSS in the delivery of services to ethnic minorities,<sup>96</sup> these included: lack of culturally sensitive services in relation to religious and cultural needs, institutional Racism, different health belief systems and procedures, etc.

The lack of interpreters will obviously limit the access of ethnic minorities to health services. This may be a breach of Section 75 of the Northern Ireland Act 1998 if the HPSS authorities have not observed their duty to have regard to equality of opportunity, in this case to access to public services between persons of different ethnic origin.

In the Eastern Health Board Area, an interpreting service is available, at a cost to health providers. As a result, in the case of ethnic minorities attending a GP surgery, the cost is likely to come out of the practice budget. The Ulster Community and Hospitals Trusts, *Policy on the Access to interpreting Services for People from a Minority Ethnic Background*, states that '*No agency can provide effective health care delivery with whom it cannot communicate (1.6)*'. The policy describes the scenario of a person requiring an interpreter, and it is clear that the onus is on the health professional to determine whether or not an interpreter is needed. It would be expected that this policy would be similar to that which is used within the Trust area that the above interviewee resides in, however the research team in this study was not furnished with the appropriate policy.

It can be deduced from reviewing policies used in other Trusts, Racial Equality Guidelines and Human Rights Legislation, that provision of interpreting services is central to the preservation of ethnic minorities' human rights. Older persons of ethnic minority origin may be subject to multiple disadvantage because they might be discriminated on the basis of their ethnicity and on the basis of their age. The impact on the quality of services and ability to access the correct health information is crucial to the protection of peoples' right to access health care.

### **Evidence of Double or Multiple Discrimination – Racist attitudes to older people**

Evidence of racist's attitudes was given during interviews although when asked specifically:

*Have you ever felt discriminated against?*

They answered no. However, when asked had they been treated badly – say attending hospital – One man said:

*“They whisper behind their hands: a Chinese man is coming.”*

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<sup>96</sup> See 2.2.

I asked him how he reacted and he said: *“I just ignore it”*.

This is the normal way in which the above respondent deals with racial remarks and it conveys that he expects similar treatment inside health settings as outside. The following account indicates how racism can result in neglect and be extremely dangerous. Samira has experienced racial discrimination a number of times by those delivering health care:

*“I went into a hospital for a minor kidney operation. This was about five or six years ago. They put me into isolation; there was no reason why I should have been put into isolation.”*

I asked Samira about the care she received:

*“The surgeons were excellent. It is those from below them. Coming round, passing remarks. They even laugh outwardly at you.”*

Samira became very distressed when talking about the time when she had a knee replacement, only two years ago:

*“When I had the operation on my knee I wasn’t washed for two to three days after. When I was ready to have my first shower, you know the way they help you to wash and your wound would be open, I was taken in the wheel chair to the showers. The woman just handed me a towel... She wouldn’t even touch me! She wouldn’t even brush my hair.”*

How did you cope?

*“I don’t know what or how I coped. I was really worried about the wound and I could barely stand, and she just left me, she just walked away. I was distraught; I was so tired and weak! I was afraid of the wound getting infected and I was very scared. I don’t know how I managed.”*

*“When I was leaving the hospital no-one walked me out to the ambulance to take me home. I am a diabetic and I knew my blood sugars were getting low, I was getting thirsty. I was in a dangerous state. They wouldn’t even assist me to go on the lift, usually people would get a wheel chair, I was left.”*

Samira repeated something that had been said in front of her by a nursing assistant to another member of staff:

*“They come here for free treatment. They come and burden us and drink this country dry.”*

Such treatment is at the very least degrading under Article 3 and discriminatory under Article 14.

In preparing policies to ensure the protection of human rights, some Trusts have established race relations policies which clearly stipulate that they will *‘work towards the elimination of racism and ensure that individuals and communities have equal access to health services’*<sup>97</sup> (Ulster Community and Hospital Trust, Policy on Racial Equality). However, some Trusts are still in the process of developing suitable policies and strategies for effectively delivering services to ethnic minorities and ensuring that they have equality of access without discrimination. It is of

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<sup>97</sup> Ulster Community and Hospital Trust, *Policy on Racial Equality*.

paramount importance that gaps in policy development in so far as race relation policies and policies for the provision of interpreters and other avenues for effective communication for non-English speaking patients are developed and evaluated to establish their effectiveness.

## 7.2 Transport

The lack of public transport and / or free transport was an issue raised by many older people, especially those living in remote areas. In this section, it is apparent that transport has an important role in ensuring older people have equality of access to services which assists the health and wellbeing of older people. The following respondent (Angela), who lives alone, highlights the costs and difficulties faced when travelling to and from the hospital:

*“I had an appointment in the Hospital, D. I have to get a lift to here (a small village) and then the bus to (at town), which has to be said, is very good. Then another bus to another town and then you have to walk to Hospital D. Well, I nearly collapsed walking up to the hospital. When I got there, I was seen and sent straight home to rest. They paid the £8 fare home.”*

“Do you need lifts everywhere?”

*“I have to pay a taxi to get my pension or go to the shop. It is a couple of pound a time. I have to travel 17 miles to attend Hospital [D] and get no expenses, even though I have to pay for taxis and all. The bus is free.” (F1)*

Angela was unaware that she could avail of a free bus from the Bus Station in the town to Hospital D. Older people may experience transport difficulties both because they live in rural areas where services may be limited and because they are unaware or what services are actually available.

Beyond issues of location, mobility also causes transportation difficulties, for example:

Ita lives alone and has had two knee operations. She relies on her neighbours to get provisions from the shop. Ita also relies on her son and daughter, who both work to take her to get her pension. Ita cannot walk to the shop, 500 metres away because of the steps and hills. In attempting to use the bus, she had to be assisted by a stranger off the bus, which she found to be extremely embarrassing.

*“I can’t get out of my own house. It’s all hills and steps, even to the shop... It’s not that I want to be taken out, or go to these clubs or anything, but I want to be able to go out myself.”*

“Is it because you can’t manage steps and things?”

*“Yes, for example, I was going to the hydro pool (following her 1st knee operation). And usually it is one of these buses with low steps, so you just step straight on to it. But this day this big bus came, and I thought right I’ll try this. So I got on alright but when I went to get off I couldn’t. It was dead embarrassing. This man had to come and lift me off the bus, and I thought never again. It’s bad enough.”*

All of the above respondents want to remain in their own homes and live independently. However, mobility difficulties and a lack of assistance results in older people being ‘trapped’ in their own homes. Although, when respondents were asked about their preference to residential homes as compared to being ‘trapped’ in their own homes, many preferred the latter.

*“I might as well give up. If I went into a residential home I think I probably wouldn’t come out again.” (Ita)*

Older people living in rural areas, who have mobility problems, may indeed be doubly disadvantaged because of a lack of public transport and increased costs of private transport.

Older people in some Trusts can avail of free transport for hospital appointments. Sorcha uses free transport that is organised through the Trusts for people attending out-patient hospital appointments. Sorcha, however, has found that using the free transport is stressful and inconvenient as the account below indicates:

Sorcha had an out-patient appointment at Hospital C at 2.05pm. She had arranged that she would be picked up by the Social services bus / ambulance. She requested that she would be picked up at 1pm. She waited until 1.35pm and was picked up then; however, the bus did not take her straight to Hospital C. The bus took another patient to Hospital D and then went back to Hospital C with Sorcha. I asked her how she felt:

*“Well I was going up to get test results, and was worried enough about that. I knew that the place up there shut at 4 and I was getting very stressed. I was afraid I would miss them altogether or that they couldn’t see me, because I knew I would have to wait for ages.”*

Sorcha added:

*“There must be a better way and someone would seriously need to look at this. There is a need for some sort of rural network or transport but all you hear is cutbacks, cutbacks.”*

It apparent that in some Trust areas free transport is not convenient. Magella has multiple sclerosis and is a full-time, wheel-chair user. Her husband, who is also an older person, is her main carer. He told me about his disgust, when the ambulance came to take Magella to her Neurology appointment:

*“Magella had an appointment with the Neurologist at 11.30. The ambulance came at 10.20 to take Magella to the appointment. But before I went and got her out I said to him, ‘Are you going anywhere else?’ He said he had to go to [a town 20miles away] and pick up someone else and then drop the both off. I told him to go and sling his hook... Did he think that Magella enjoyed sitting in the back of an ambulance for an hour before getting to her appointment. The driver said that he had to pick Magella up first because that was the way the ambulance controller... told him to do it.”*

“So what happened?”

*“Well he had to come back for Magella and it never happened again.”*

Magella added: “*But sometimes you would be waiting for an hour and hour and a half waiting for a lift to get home from hospital. You know what is lacking, a taxi that can take wheel chairs. We would pay rather than have to sit and wait!*” (MKO)

Whilst it is acknowledged that any kind of service is better than none, improvements within transport and allowances are required to ensure older people have equality of access to services throughout Northern Ireland. Trusts throughout Northern Ireland commission transport services with private firms, voluntary organisations and the Ambulance Services for the delivery of transport services.

The Eastern Health & Social Services Board (EHSSB) Standards for Hospital Services require that transport should be arranged by GPs for people on medical grounds if they require them to attend hospital appointments. Also the document states that people should not normally have to wait no more than 90 minutes for special transport home from hospital if required. The practicalities of arranging hospital transport for patients are clarified in for example *Procedure for Ambulance Desk* (Ulster Community and Hospitals Trust). No specific delivery aims are mentioned in the policy; however, it is clear that when a patient who is a diabetic has a particularly long wait, they should be a meal. It would be more appropriate if delivery targets for ‘non emergency’ transportation were published so that users could gauge if inefficiencies exist and if they are not receiving the standard that they should expect.

This report encountered no policies which reviewed or detailed current DHSS&PS position on transportation of patients to and from hospital, primary care or day-care. Although the DHSS&PS have referred to their work with the Department for Social Development which is reviewing delivery and provision of transport services, this review includes services to patients, particularly those with mobility problems and the DHSS&PS advise that they are currently developing a regional transportation policy.

As section 2 of the *Chronically Sick and Disabled Persons (NI) Act 1978* imposes a duty on HPSS authorities to provide facilities for, or assist a person with, travel if he or she is provided with services under that section, such as a day centre, educational or recreational activities (NIHRC, 2001

The benefit of transportation was highlighted in interviews: a community bus brings respondents to a day club where they socialise and sometimes receive help and advice. The ladies were asked what would happen if they had no bus to collect them or club to go to;

“*We would stagnate.*”

“*Well, we might as well pull the blind down and die.*” (HFG)

The following respondent (Jack) has had a stroke and requires assistance from carers. He lives on his own. He bought himself an electric buggy and I asked him what it meant having a means to get out and about:



*“It’s a different world. I would be stuck here otherwise. But I can go out to the shops and yarn with folk and go to the shore and that, and visit neighbours. I think it would be awful having to sit here all the time.” (Jack)*

In summary, the provision of transport is vital to ensuring that older people have equal access to services and facilities. Providing a means by which older people can get out of their homes has a huge impact on their physical and mental health.

### **7.3 Adaptations**

Arguably the provision of heating adaptations is one of the ways in which the State performs its positive obligations to allow older persons the right to exercise their Article 8 rights, and so has an important role to play in the lives of older persons. Yet, Angela described how:

*“They took away my home-help after a few weeks and said that I had central heating and didn’t need the fire lit, but I have an old house you see, and I need the fire lit to stay warm.”*

*“Why, is your house not fully insulated?”*

*“Well, it’s an old house, it hasn’t got those walls, you know for the insulation.”*

*“Cavity walls?”*

*“That’s it, and they don’t hold in the heat. But the social services came and looked around the house and took off the home-help because she said I had central heating.”*

*“What about the Housing Executive, or Fold say, did they look at your house to see if they could increase the insulation?”*

*“Yes, but because of the walls they said that there was very little they could do. You know it gets very, very cold. For me to put on the heat full blast it is too expensive.” (HFG)*

It is apparent that in this case a policy was applied without regard to other important factors, such as the energy efficiency of a home and the cost of heating old houses. Grants are available from the Housing Executive and Fold to renovate and repair housing. It can be argued that home-helps alone cannot alleviate the problem of ‘fuel poverty’. Tackling fuel poverty is one of the areas signalled within the *Health and Housing 2000 Strategy*, which highlights that in 2000, 28% of all households live in fuel poverty and acknowledge that fuel poverty can lead to winter deaths particularly among older people. The Health and Housing Strategy indicates that the Housing Executive aims to alleviate fuel poverty however this must be done strategically with DHSSPS. Joint funding to alleviate the problem of fuel poverty has been called for within the Strategy document. Housing providers need to take account of the International Plan of the Action on Ageing (1999) which states *‘housing for the elderly must be more than mere shelter’* including where appropriate, the improvement of their homes to meet their needs. Trusts should work in conjunction with the Housing Executive to establish measures to deal with the difficulties faced by older people in terms of fuel poverty and the impact these have on health. The issue of ‘fuel poverty’ has been adverted to by the United Nations Committee on Economic, Social and Cultural

Rights. In its latest assessment of the UK's compliance with the eponymous Covenant, it has urged the State to 'relieve the situation of those who are "fuel poor".<sup>98</sup>

A small number of those interviewed had adaptations completed in their homes. However, this tended to be stressful and for the following respondent (Jack) who had had a stroke, it meant that he was placed in a nursing home temporarily. He was very unhappy with the experience of being placed in a nursing home, which catered for people with dementia;

*"I was in hospital for a few weeks because of the stroke I had. And the men started work straight away, or so I thought. The last stroke put me off my feet and so they had to widen the doors in the house and they built on a new room with a bathroom. I wanted them to put a lift in, because my next door neighbour had one in, because he has a stroke. They just cut a hole in their living room, but I was told I couldn't get that. Well I can't understand because the houses are exactly the same. Anyway I was in hospital for a few weeks and they were supposed to start the work. And as far as I know they were in 1 day and back another. And then when I was ready to come home, the place was in such bad shape I couldn't get home, so I had to go to a nursing home."*

Who had organised this?

*"Shelter organised this with a contractor. They started the last day of April and weren't finished until September. You should have seen the shape of this place, and they would come one day and not bother another. They got me to sign the completion sheet and you see I made a mistake, they added the start date after I had signed it and you see I didn't read it. I complained to Shelter and they checked the records and they said there was nothing that they could do because I had signed the completion."*

Jack stated that because he owned his own home he felt he had to pay more for the adaptations and he could not understand why they had to build an entirely new room because he lived in the house on his own. His neighbour does not own his Housing Executive house and they installed a lift from the living room to the bedroom. As a result of delays, Jack felt he spent unnecessary time in a nursing home, in which he could not communicate with other patients.

*The Joint Fundamental Review of Housing Adaptations Service* acknowledges many of the difficulties highlighted and recommends the increase in occupational therapists, speeding up of the processing of adaptations and the improvement of the quality of the service. Article 4 of the Additional Protocol of 1988, although not ratified by the UK, concerns the rights of older people to social protection whereby states adopt or encourage appropriate measures to enable older people to live independently in their homes, such as additional resources for adaptations, and the provision of health care. The housing adaptation services need to acknowledge that they are potentially breaching the rights of older people by displacing them from their homes for unnecessary lengthy periods of time.

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<sup>98</sup> Concluding Observations of the Committee on Economic, Social and Cultural Rights: United Kingdom of Great Britain and Northern Ireland, United Kingdom of Great Britain and Northern Ireland - Dependent Territories. 05/06/2002. E/C.12/1/Add.79, paragraph 39.

## 7.4 Home-helps

Throughout this research there was discontent with the availability and the level of assistance provided by home-helps. The following accounts and comments highlight dissatisfaction:

*“You need to be paralysed before you would get any help.”*

*“I pay £5.40 for home-help. I had angina and my husband had Alzheimer’s and we got damn all. I was let down a bucketful!” (HFG)*

*“I have arthritis. And you know I’m not really able to go about. I can make a cup of tea but I am paralysed on the left side and I have a weakness. My family come in and make my meals every week. But I really need a home help. The woman from the social services came and told me that I would have to go into hospital first before I could get home help. I don’t want to go in and I feel rotten that I have to depend on my family all the time.” (DCG)*

and even when help is provided:

*“They can’t even lift a chair.”*

*“They need to be able to clean.”*

*“When the home-help is away say, on holidays, or is sick, no-one comes in their place.”*

*“There are many faults with home-helps, but most of all, they don’t come long enough, they are not allowed to do much and then before you know it they are taken away.” (SCG)*

Sally cares for her daughter who has epilepsy and her husband who has [had] a stroke. Sally had a major operation early last year (2002). She said:

*“I have, I suppose, always just got on with it and cared for my husband and my daughter. But after my operation last year I needed a home-help. I was given a home-help for 6 weeks and was told that was that. I just had no energy to fight with them, but it was totally inadequate and really and truly what can anybody do in 15 minutes?” (ACG)*

The criteria used to determine home-help is different across Health Trust areas. Samira describes how in her case disparity is evident when different social workers apply varying standards to the same case:

*“When I came out of hospital the last time from my knee operation they were going to cut my home-help at evenings and weekends. The social worker that I was normally used to was changed and this new social worker was forcing me to stay with my daughter at weekends because she said that she could help out. I refused and then the manager got involved. They requested a meeting with my daughter, me, the social work manager and the social worker. They asked my daughter would she have any objections. My daughter lives with her two children and her husband in a two- bedroom house. They would have had to put me in living room. I felt humiliated and my daughter felt humiliated, she would not speak out.”*

How often was this for?

*“Holidays and weekends, when the home-help would be off. There are no railings on the stairs and I would have had to use a commode.”*

So what happened at this meeting?

*“Well, my daughter is quiet and she wouldn’t speak up. So they cut it. But I sent them a letter back and said that I would be seeking justice and would be seeking legal advice. Then my old social worker came back and gradually everything went back to the way it was before.”*

(ILB)

The above comments highlight both how resource issues are forcing older people to make alternative care arrangements and how more can be achieved by those who are willing to be assertive; this is further examined in later sections.

The reduction of domiciliary services, when they are not replaced by private services, could be viewed as a breach of Article 14, of the European Social Charter, which protects the right to social welfare services in the UK (NIHRC, 2001). States are under obligation to seek to improve, over the years, the development of their social welfare services. It could be suggested that because Samira was asked to sleep in a living room, predominantly used by a young family and use a commode because there is no downstairs toilet that there may be a breach of Article 3 which protects older people from degrading treatment and a loss of dignity, though the treatment endured would have to reach a certain level of severity to engage that Article (NIHRC, 2001). The reduction of domiciliary services, in this case, could be challenged via the complaints procedure or by a judicial review action.

*The Future Provision of Home help in Northern Ireland (DHSSPS)*<sup>99</sup> indicates that at the time of writing the provision of home help would be dependent on the assessed needs of individual clients. However, the circular indicates that the service should be provided to those over 75 and those in one of the listed priority groups. Overall, the circular makes it clear that the home help service is to be provided to individuals or families when failure to so provide would result in deterioration of their physical or social circumstances.

Each Trust operates its own assessment and uses its own guidelines in providing home help. It would be appropriate to establish how home-help services are applied throughout Trusts and how the service is monitored and implemented. Older people should be made aware of the rules governing the service and the type of assistance provided in the delivery of home help services, this would abate confusion and disappointment.

## **7.5 Information**

As indicated in the previous sections, some respondents were unaware of the availability of services and their entitlement to services. For instance, in two focus groups, individuals were unaware of laundry services for those people that they cared for. Older people were unaware of a central point for providing information. As a result, older people may not be accessing services that they are entitled to because no-one has the duty to inform them of the availability of services.

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<sup>99</sup> Circular HSS/18 dated 1980 and revised 10 April 2003.

The following account highlights the need to know how to access services:

Ethel also mentioned something at the end of the interview:

*“See since the last time I was in the hospital, I really haven’t had a good shower since then. (Ethel was on holidays for a few weeks and has been at home for two weeks now.) I can’t get in and out of my bath and so I can’t wash properly.”*

“Were you not given a phone number or anything to ring about getting access to services when you left the hospital the last time?”

*“I was, but I lost it, and I really need a shower.”*

I contacted Social services and they asked me to get Ethel to ring them. This illustrates the need to increase older people’s awareness of services, what is on offer and how to access them

During fieldwork, the researcher often was quizzed about services. Some queries were solved within group discussion. However, on two occasions the researcher had to follow-up enquiries with outside agencies thus evidencing the need for easily accessible information about services.

Molly, who lives alone with no family nearby, suffers from arthritis and osteoporosis as well as being an asthmatic. She pays £2 for a taxi to the doctor, she cannot walk very far. She also pays £15 each way to go to the hospital, as she cannot get the bus and was unaware that of any other form of free transport to and from the hospital.

Older people also indicated that they needed assistance in helping them fill out forms and requested that forms were made less complicated as the following account illustrates:

Margaret’s husband had passed away and she cared for him for five years following a stroke. She said:

*“John used to do everything, like filling in forms and all that sort of thing. But when he had his stroke I had to do everything. The forms you had to fill in were, well... ah... They need to be less complicated.”*

*“We went to Ballybot House and they told us what people were entitled to but they won’t fill them in for you. And for all the hassle, you may end up with nothing”* Peggy added. (HFG)

Dissemination of information via a central information point that also supports older people in accessing various services would be invaluable. The UK has ratified the European Social Charter, and Article 14 (1) requires a state to ‘promote or provide services which would contribute to the welfare and development of both individuals and groups in the community.

## **7.6 Rehabilitation**

The following account highlights the need for development of rehabilitation services to support those who wish to remain in their own homes and live independently:

Ita has just had her second knee replacement, she said:

*“I lost confidence to go out. I don’t know that if I go out that I can manage getting back again. And I mean I can’t rely on neighbours all the time or my son to help me out and back again.”*

Ita has full intentions of rehabilitating herself and becoming more mobile; however, she needs assistance. She hasn’t asked for any help because she thinks there is none, or she hasn’t been told about any. She is unsure about how she will improve her mobility if she doesn’t get the right kind of assistance; she is worried about her future.

*Investing for Health* (DHSSPS, 2000) identifies the need for the provision of services so as to ‘encourage independence, support older people to live in their homes’. The Priorities for Action March 2002-2003 (DHSSPS) aims to improve rehabilitation services so as to avoid dependency and Ita’s story is an illustration of how an individual’s dependence on social services could increase if she doesn’t receive further assistance. As a result of Ita’s unmet need, there is a possibility that her health condition could worsen.

*Towards a Society for All Ages*<sup>100</sup> highlights that rehabilitation services, along with others require expansion. Ensuring independence and ability to take part in social and cultural life with respect and dignity is incorporated in Article 25 of the EU Charter of Fundamental Rights.

## 7.7 Waiting

Older people felt that waiting for hospital appointments and operations was the norm. Many explained that *‘that’s the way it is’*. None of those interviewed felt that they had to wait longer because of their age. Some respondents’ conditions worsened because of their waiting time as the following conversation with a focus group indicated:

Regina said: *“I was waiting for a rail for 3 years.”*

Anne added: *“Sure I was waiting on a shower for 2 years and still haven’t got it in. I’m half-blinded in one eye. I can’t get out without someone being with me because I can’t see. The other eye is going because of it, it’s strained.”*

“How long have you been waiting on an operation?”

*“Two years now. I don’t go out of the house on my own because I’m afraid I’ll trip over something. I already fell and fractured my wrist (she shows me the bandage), so I’m afraid of going anywhere really.”*

“Has your GP helped you up the list a bit?”

*“Well he said that I’m down for a cancellation if one becomes available. But I’m looking into it privately, it costs a lot of money but my children said they will help pay for it, because I need to get it done and they hate to see me like this.”* (HFG)

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<sup>100</sup> UN 1999.

Older people had difficulty accessing podiatry and some never receive treatment as the following account illustrates:

Molly's doctor referred her to the Podiatrist for treatment for a corn:

*"I found that the corn was unbearable... I was waiting two to three months before I got word back that they could not see me because they were prioritising other cases, those who are; Diabetics, Rheumatoid Arthritics, those with Comprised Circulation to lower limbs, those on anticoagulants, steroid or immunosuppressants, those with biomechanical problems, those with acute infections and those with terminal illnesses. The letter also added, 'Should your condition change we will reassess your position on the basis of further information from your GP'."*

Molly was considered as low priority: *"I feel that I was not treated equally."*

*"So what has happened since then?"*

*"I got the two nails and the corn which was between the big toe and wee toe and I picked and squeezed it out. Sure I think I could have done some damage and could have caused myself some blood poisoning."*

Kim says the only thing that she really needs at the minute is podiatry:

*"I have just given up on it. I have arthritis and my toes and that are getting all twisted. I think it's been 8 months."*

Within the literature review, it was established that within some specialisms, such as ophthalmology and cardiac surgery waiting times are lengthy. The case of *Passannate v Italy*<sup>101</sup> notes that an excessive delay of the public health service in providing medical service to which the patient is entitled and the fact that such delay has or is likely to have a serious impact on the patient's health could raise an issue under Article 8.1 of the Convention.

On reviewing policies for management of waiting lists in Ulster Community and Hospital Trust, patients are classified in one of four categories: Category 1 patients are to be admitted within one month and Category 3-4 to be admitted on clinical priority and within the Patients' Charter timescales. The policy indicates that medical staff are responsible for placing each patient into one of the waiting list categories according to clinical priority. At no point is age mentioned within the policy as a determining factor in waiting times.

It has been suggested through anecdotal evidence that:

- A minority of consultants and other medical staff may tend to treat younger patients before older patients because of the belief that benefits for younger people outweigh those for older people.

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<sup>101</sup> NIHRC 2001.

Within the literature review, authors point to cases whereby older people are offered more palliative care and less surgery or intrusive forms of treatment.<sup>102</sup>

Further research is required to establish the validity of this anecdotal information, by reviewing the decisions of committees who are responsible for planning surgery.

## 7.8 Medicine and Illness Management

Medicine management and review is seen as crucial to prevent reactions and further illness. It was evident in the interviews that some older people received scripts without their case being reviewed;

Anne said: *“I have been on tablets for my angina for 6 years, but I haven’t seen a consultant nor a doctor for three years. I was supposed to be recalled and I was never and so I never bothered about it.”* (HFG)

As a result of an alleged prescribing blunder, Magella, who has MS and was admitted to hospital, as she describes:

*“I ended up in the Royal in fact and I was in there for a month and in Foster Green for a month.”*

“What happened?”

*“It was really due to mismanagement from the GP. I was being diagnosed over the phone and was prescribed cortisone. I became so depressed and was admitted to the Royal Neurology department. They told me I was not to take Cortisone. Because of this I was in hospital for 2 months. I have since learned that I should have been examined and that I should have had my blood pressure taken. I have known the GP from school days and I suppose familiarity and all that and we had asked him to call out but he just prescribed without seeing me first. Maybe it’s because he was an acquaintance and he didn’t think it was worth his while, I don’t know.”*

The above account supports information gathered during the literature review in highlighting that misdiagnoses and inappropriate prescribing occurs.

## 7.9 Consent

In two cases, respondents felt that ‘consent’ was not sought. Both felt that they were forced into having tests and treatment when they did not want them:

Ethel has a blood disorder and she attends a consultant in Hospital A. She had concerns about what is meant by consent to treatment. She had to get an oesophagotome, (examination of the oesophagus). She was told that it was necessary and she asked:

*“I asked what it was going to show up and the doctor said it might show up what the problem is. Well I said if it did show anything up then fair enough. I wasn’t looking forward to it at*

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<sup>102</sup> Turner *et al* 2001 and Bowling 1999.



*all. They also told me that there was a slight chance that I would haemorrhage and they kept me there for a couple of hours before they sent me home. On the way home I knew I wasn't feeling well. Then when I got home I did haemorrhage, and actually went unconscious because of it. They did ask my daughter to stay with me when I got home, so luckily she was there. So that was that and I was taken back into hospital again. Then they wanted to do the same examination on me. I didn't want it done, especially not after the last time, because it is dreadful, you feel that you can't eat or drink properly for weeks after. I felt really pressurised into having this thing down my throat and they never gave me a real good reason why I needed it done again. I relented and the results were inconclusive. I'm very cross because I felt really pressurised and I gave in because the doctor got really cross."*

Ethel also added: *"It really is frightening when you don't know what to expect."*

(Ethel's friend who also attended the group meeting told me quietly that Ethel was dying; she knew herself. The results of various tests confirmed what she already herself knew. The doctor was however not forthright with information.)

In April 2002, Magella said that she had to go back to the hospital because of pressure sores on the right and left thigh and an ulcer on the right ankle. She said that she had *"a run in with the GP"*:

*"He wanted to give me antibiotics, I'm always on antibiotics. I was querying the options. He was questioning why not and he lost the rag with me. He started shouting at me and was very angry and aggressive."*

*"Why was this do you think?"*

*"I think because he felt I was challenging his judgement. Really all I wanted to do was examine the options and see if there was anything else I could do."*

*"Did he give you any options?"*

*"He basically said that there were no other options and I would have to take the antibiotic or suffer the consequences."*

*"He was ignorant"* her husband added.

*"Two days later he arrived at the house here, with apologies and flowers. I suppose everybody has bad days."*

*"Did he explain why he had become so angry?"*

*"No, there was no explanations, he apologised for being so blunt. He then was helpful as he talked to the consultant in the hospital about my pressure sores and got me admitted relatively quickly, on the 22<sup>nd</sup> April."*

Time taken to fully explain options and reasons for treatments or tests both reassures and informs patients.

Good practice guidelines on seeking consent from adults<sup>103</sup> clarifies that it is the absolute legal and ethical right of the patient to give consent with appropriate information and not under duress. The policy proposes that seeking consent is much like ‘joint decision-making’ and proposes that health professionals and patients should be in agreement on the best way forward. This was clearly not the case in the above accounts.

## **7.10 Discharge, Planning and Delivery of Services**

The following account highlights difficulties faced by carers in organising and planning care when the people that they care for return home from hospital. The respondent (Lawrence) points out that time and perseverance is required so that ‘seamless’ services can be provided. While speaking, he illustrated stress and dismay about the difficulties faced by him as a carer.

The provision of one point of support/information would be useful so that carers can make arrangements, as suggested below:

Lawrence cares jointly with his siblings for their mother. He told the story of his mother who is house bound and, as he puts it, “*Is a bit doting*”. As a result someone, either Lawrence, his brother or sister, stay at night with her. His mother was getting ready for a cataract operation and he said:

*“Basically we knew my mother would be in distress following the day of the operation and we wanted for her to be kept in a night however the hospital didn’t want to do this. The operation was put off and put off for a few months and it took numerous phone calls with the hospital, and it wasn’t just one person you were ringing, it went from one to another and took ages. So when we got that sorted we were told that we would have to administer drops into my mothers’ eyes 4 times a day. We could manage it in the morning and evening, but because we are all working and my mother couldn’t do it herself, we had to arrange someone to do it for her. But the District Nurse said that she could only do one in the morning and it wasn’t convenient for her to do it in the afternoon. But what could we do? The nurse was ringing my mother and was asking her what she thought. And my mother wasn’t really saying anything and didn’t want to argue, because she feels that if you say anything it might effect what you get. You see she would be scared. It took about six to ten phone calls before we got that sorted, and really and truly all we needed was a meeting between us (the carers), community nurses and the hospital to get this thing sorted. It would have saved a lot of time and grief.”*

***“Why couldn’t your mother put the eye drops in herself?”***

*“She could mix up the medicines as it is and she had eye ointment as well, you see at this time she couldn’t see very well either.”*

***“What do you think should have been done?”***

*“Just what I said, a meeting initially with the hospital about the day-op and what was going to happen, make the arrangements for getting her home and the treatment she required at*

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<sup>103</sup> DHSSPS March 2003.

*home. This could have been covered in one meeting, instead of a load of phone calls. You know, you really have to be assertive.”*

The above account shows how the joint planning of care and delivery of services is difficult. As already indicated, the following respondent (Jack) was placed in a nursing home because his adaptations were not completed on time. The placement in a nursing home that cared for dementia patients was not appropriate for Jack. He also emphasised that having his daughter’s support and help was crucial to him managing and ensuring services were in place. He called the nursing home “Hell Hall”. I asked him why he called it that:

*“All the people there did not have their own minds. There was one boy there and I would have known him all my life; I went to the same Primary School as him and he didn’t know me, or anything. The people there had no senses. Nobody corresponded with you.”*

“How did that make you feel?”

*“Made me feel awful, I didn’t have any other options. The staff in there did their best and I would spend my time chatting to them. Beside the dayroom was a private room for visitors and, well, I spent my time in there.”*

“Did they give you anything to do?”

*“Nothing. I had an old television and I spent my time in there and sat and watched it.”*

“So how long did you have to stay there?”

*“A few weeks. Sandra (his daughter) kicked up a fuss and she got the house cleaned up enough to get me home.”*

“What would you have done if you hadn’t had Sandra?”

*“I don’t know what I would have done. I probably would have still been there. Sandra is great you know, she helps me out.” (HGB)*

Jack had not known until the previous day that he was going to be placed in a residential home. He was not consulted and felt very much uninformed about what was going to happen to him. Jack was told: ‘you’re going tomorrow’ and that was the only information he was given. It is possible, because he was viewed as disruptive, that staff were distant, thus resulting in him not being made aware of the choices available or arrangements being made.

It is evident that in this case the planning and delivery of discharge and community services are not provided in a ‘seamless’ manner. The Report on the discharge of patients, *From Hospital to Home*,<sup>104</sup> reports that within the Assessment of Need, the Trust has a method of assessing needs... ensures the involvement of service users and carers/ relative at different stages, including decision making and agreeing objectives. The joint discharge procedures for Altnagelvin Hospitals and Foyle Health and Social Services Trust aim to ‘ensure the safe and appropriate discharge of patients from hospital’. The objective is to ‘provide a safe and timely discharge to an appropriate environment consistent with patient choice’. In the above account it is apparent that Jack would have rather been in a more suitable ‘environment’.

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<sup>104</sup> SSI 1997.

Those who are happy with the services they now receive have alluded to times when they have had ‘to fight for things’. For instance, when asked were there times when Magella had difficulties in getting things that they were entitled to, Sam said:

*“Well it can be very difficult. I had a meeting with the District nurses, the hospital nurses and the social services before Magella came out of hospital that last time. We were planning her care and kind of out of the blue the manager of the social services said that Magella was being uncooperative, but there was no call to say things like that, because the services hadn’t been delivered yet. So sometimes they can be offensive.”*

Majella added: *“And I suppose we have fought with them, if things weren’t right, but you know you have to. We can fight our own corner, and you see Sam has worked in hospitals and has contacts so you know what’s what.”*

This sentiment of ‘fighting your corner’ was expressed by a carer who looks after her husband who had had a stroke. She said that she was extremely happy with all the help that she has been given. For instance, the couple have had a downstairs room adapted; she receives respite; he attends day-care and also has carers in morning and afternoon to assist in washing and toileting. She spoke at length about the great care they received and how happy they were with services. However, when asked had all the services been provided that she required, she said:

*“We had to fight at times for things. For instance I needed the second hoist to get him out of bed, say in the evening or at night. I couldn’t manage him all by myself. The one hoist wasn’t enough; you need two to operate it. So, it took a while but I got it. It was too much trying to get him to the toilet, say in an emergency, it was terrible.”*

It is apparent that the above carers, who are all over 65 receive support from social services; however, it is apparent that all have had to ‘fight’ for some of the services they now receive. Their experiences confirm the need to further support carers as set out in the 2002 Carers Strategy<sup>105</sup>.

## **7.11 Unmet needs**

Throughout interviews, there were services that were required by respondents but were not available to them because of resource constraints. Day centres, transportation and home-help were some of the needs expressed by older people. The issue of whether resources can be considered by HPSS authorities in the context of service provision is a crucial one which has been the subject of litigation in the House of Lords,<sup>106</sup> and which lies at the heart of discussions about the implementation of economic and social rights and the performance of positive obligations. In the following account, Ita had to go into a nursing home because night sitters/carers were not available for the first six weeks following her discharge from hospital after her second knee replacement; she felt she had no other option:

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<sup>105</sup> DHSSPS.

<sup>106</sup> See *R v Gloucester County Council ex p Barry* 1997 AC 584 and *R v Sussex County Council ex p Tandy* 1997 3 FCR 525.

*“I wasn’t great when I came home. I have the toilet upstairs and I had to have a commode here in the living room. My next door neighbour is very good. She came in and helped out, but you know (sigh) I found it embarrassing because she had to come at times and empty the commode out, and you know, neighbours shouldn’t have to do that sort of thing!”*

Her son brought the bed down to the living room for her and her family helped out a bit, but she felt that this wasn’t enough:

*“I really needed 24 hours care, and I knew I was struggling. You can’t expect someone to be here for 24 hours, you know. The carers came in and helped me but I couldn’t manage I was too poorly.”*

“What about your son or daughter, did they stay?”

*“Well, I didn’t want to be a burden on anyone. My daughter is on her own with two kids and my son works night and day shifts, so it was real hassle for them, and sometimes they couldn’t be here.”*

The care managers suggested that she should go into a home. They felt she needed someone there all the time. Ita also felt that she needed someone to be there all the time:

*“I was so miserable.”*

*“What I really needed was someone to be here at night. There was a waiting list for night sitters and there was days here that I couldn’t go to the toilet and couldn’t have a bath. It does wear you down.”*

“So you couldn’t get a night sitter?”

*“Well you can’t expect everything. You can’t expect 24 hours care.”*

“What about the first time you got your knee done, what kind of help did you get then?”

*“I had a carer come in and helped me with dressing and all that, and I had a home help that cooked and cleaned a little. Ah, we also had the laundry service. It was only in three days a week and with my husband, sure it wasn’t enough whenever you think about it, the sheets you’d have to clean.”*

“So the second time, did you go into the residential home?”

*“Yes.”*

“How did you feel about that?”

(Long pause)

*“Well I suppose I was on my own. I liked being at home.” (pause) “I don’t get myself into a rut and I like doing things myself.”*

Decisions to ration services which affect people’s ability to remain in their own home or maintain family relationships’ may impact on enjoyment of Article 8 rights which include respect for home, family and private life. In this case, Ita required temporary assistance at night in addition to what she was already receiving in the daytime. It is not possible to discern whether the offer to place Ita

in a nursing home instead of offering night sitting service was because of resource constraints or financial decision making. It is clear that Ita would have preferred to have stayed at home.

## 7.12 How Older People Felt Treated by Health Service Providers

Although older people, who were approached in this study, mentioned health workers / professionals who were felt to be excellent, they also described incidents whereby they felt undervalued and badly treated, as the following comments illustrate:

Magella said: *“Once you come, they don’t want to know you.”*

The researcher asked: *“Do you really feel like that?”*

Anne added: *“There are some very good doctors and nurses out there but they have so much and you’re just another person in the queue. We all have been waiting for so long for different things.”*

*“You pay your stamp you might as well stick them to the ceiling!”*

*“I remember being in hospital and this sister there, she was serious. She would talk to you as if you were not really there you know. Oh, I just get up to high dose thinking about it!”*

Anne added: *“It means a lot to you if someone treats you as a person and is nice to you.”*

*“It gets on your goat if they are ignorant”,* Peggy complained. (HFG)

Ellie who is over 65 and caring for her mother complained:

*“You know they would talk over my mother as if she’s not all there.”*

Ellie described an experience of her mothers:

*“My mother was in hospital and she says that there were four or five nurses or doctors standing around her bed.”*

*“Did she know who they were?”*

*“No, and she didn’t find out. They just looked at her chart and my mother said that they just talked away among one another and then walked off.”*

*“Did not even one introduce themselves to her?”*

*“No.”*

Jayne who lives in a residential home advised the report:

*“I had a stroke about a couple of years ago. I was in Hospital D. They kept me there for observation. I had one experience where there were about 10 of them, and I don’t know what they were talking about, they were standing around my bed and weren’t talking to me.”*

*“You’re a number”* Lucy added.

*“They don’t explain things..... But maybe they don’t tell you in case you’ll worry”* Jayne said.

Over the last two years, Jack has had three strokes and two heart attacks and has been admitted to hospital numerous times. When discussing Jack’s most recent experience in hospital, I asked Jack had the health service staff talked to him about the care being planned for him or his condition:

*“Well you know it’s like it is a big secret; they don’t (the doctors or nurses) communicate much with you in hospital. It wasn’t until I came out of hospital and I was talking to my GP that I realised how sick I was. You see, I had mastitis and nobody in the hospital told me that.”*

*“Do you think that they didn’t tell you so that you wouldn’t panic or worry?”*

*“I suppose but I would have liked to have known what was wrong and what was going to happen. All I was told was that I was going tomorrow.”*

Procedures and guidelines were not followed in Magella’s case. She has MS. The following incident happened five years ago:

*“I had an episode in the hospital with two student nurses. They were assisting me out of bed. I told them – You are not holding me properly, and they dropped me. Sam was told that I had taken a spasm and fell.”*

*“What did you think about that?”*

*“I was gob smacked!”*

The incident was not reported and the researcher asked why:

*“Well, I let them know that I was not happy, and in a way used it more cleverly. Put it like this, they did everything in their power to keep me happy.”*

The following account by Jack indicates the need for all those working and visiting hospitals as well as lay people, to be aware of hygiene and patient care:

I asked Jack how he had been treated when in the hospital and in the nursing home:

*“Oh, I was a bad boy.”* he said.

I asked how? He told me that a visiting dignitary and his wife were visiting the wards in Hospital B. Jack said he was sitting up to eat his meal, and the visiting dignitary’s wife came over to him and said:

*“‘Ooo, lovely meal, lovely meal, yum, yum’, and then she prodded it with her finger. I asked her would she eat a meal if he had prodded it with his fingers; with this the dignitary’s wife walked away.”* and Jack added, *“I fired the dinner after her. She was a stuck up, obnoxious cow, prodding my dinner with her finger and talking to me like that!”*

Jack was then changed to another ward the next day. Following that he was placed in a nursing home, which he called “Hell Hall”.

Samira also describes how some community health professionals were disrespectful towards her:

*“An OT came to assess me (Samira has a de-habilitating disease that causes her to drop things). I said to her that I drop things and have no sensation in my hands, and she said: ‘You haven’t been burnt or lost your fingers!’”*

What did you think about that?

*“I feel many don’t have any respect; who is our witness, only God above.”*

Ita has had two knee replacements carried out over the last five years. The first knee replacement was not a success as Ita explains:

*“I had the first knee done about five years ago. I had it done in Musgrave and the joint was too big and as far as I know they had to prise it in (Ita is under 4ft tall). With that they actually fractured my shin you know, while they were doing it. Because the joint was far too big for my legs, sure look at the size of me!”*

Subsequently, with her second knee operation, a specially made smaller sized joint was made for Ita.

None of the above complained. For example, Ita was unsure of whether this could happen normally (the fracturing of her shin), Samira felt that it was her word against the Occupational Therapist’s, and Jack, as he said in his own words, was a ‘bad boy’ and because of his reaction he did not complain.

An evaluation of the HPSS complaints procedure<sup>107</sup> stated:

*‘A very common and pervasive source of dissatisfaction among complainants is poor attitudes of staff-including both clinical and managerial staff. Complainants often mention lack of respect; lack of sympathy and understanding; patronising, aggressive and arrogant attitudes.’*

As a result of this kind of behaviour by some staff within HPSS, it is perhaps understandable why the older people within this research declined to complain.

### **7.13 Summary**

The above accounts of older people highlight that they suffer from a range of problems associated failure to meet need and inconsistent delivery of services.

Older people in this research were largely undemanding and ‘accepting’ of the services delivered and unable to gauge discrimination because:

- They are unaware of standards against which they may measure their experiences (although the DHSSPS advise such work is well underway).
- There are no published criteria for the care services available nor are there any lists of the services available.

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<sup>107</sup> York Health Economics Consortium 2001.



- They are unaware of their position on waiting lists.

The DHSSPS acknowledges these difficulties in its consultation document, *Best Practice – Best Care*,<sup>108</sup> which states:

*‘There are still, many gaps and inconsistencies in the way standards and guidelines for services are produced and applied.’*

It is not evident that work conducted within Trusts to reduce inequalities and to establish standards based on ‘robust research and evidence of good practice’ has begun. There is no method of monitoring how services are delivered, to whom and why. Clear guidelines and standards must be disseminated and accessible to all.

Research shows that the majority of complainants are unhappy with the current complaints systems and have not been satisfied with outcomes. As a result therefore, the current system may not build the confidence which older people need to be able to make a complaint.

## **8.0 Conclusion**

Throughout the interviews, older people related instances when they have considered that they were treated in a degrading manner. Unmet need and inconsistencies in the delivery of services have been highlighted. Throughout these accounts the potential breaches of the HRA are referred to. However, unless older people are made aware of the standards of health care that they should expect, they will not come forward to complain or seek assistance from support groups, or the Northern Ireland Human Rights Commission and, therefore, any monitoring will not be reflective of this group of users.

There is a legal obligation on HPSS to ensure age discrimination or double/multiple discrimination does not take place.

Further resources may be required to address the growing number of older (75+) and very old (85+) people. At present, there are unacceptable waiting times of more than five weeks for nursing and residential home care. Indeed, 11% of priority cases had to wait six months or more for occupational therapy services (2001/2002). The DHSSPS should address the unacceptable waiting times particularly for those waiting for housing adaptations, domiciliary care, ophthalmology, urology and cardiac services.

Anecdotal information gathered from discussions with health care providers, particularly in secondary and acute care, suggests that professional pragmatism in the rationing and the delivery of health interventions impacts on the nature and type of care and treatment delivered to older people.

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<sup>108</sup> 2001 p 19.

Furthermore, much can be done to ensure that older people have equity of access to services and are receiving high standards of care. At present there is limited transparency in the prioritisation and delivery of HPSS services / treatment. A regional benchmark whereby older people can readily judge their experience against other users of health services is not available.

At present there is limited transparency in the prioritization and delivery of HPSS services / treatment (this is rightly placed within the medical judgment of specific professionals). However, increased transparency would allay fears or feelings of discrimination and ensure accountability of decision makers.

## 9.0 Recommendations

- Public authorities should specifically carry out HRA-audits of policies and service delivery in respect of older persons, with a particular emphasis on identifying occasions on which their positive obligations in respect of Articles 3 and 8 of the Convention Rights might be breached. The NIHRC should offer some guidance to public authorities in respect of this task.
- The NIHRC should recommend that the UK government ratify the revised European Social Charter, and to recognise the right of collective complaints procedure, and that the International Covenant on Economic, Social and Cultural Rights be incorporated into domestic law. The Committee on Economic, Social and Cultural Rights has also recommended the latter course of action in both of its last two Concluding Observations on the UK's periodic reports.<sup>109</sup>
- Any future equality legislation, such as the Single Equality Act for example, should include age discrimination in the provision of health and social services, and should not be confined to age discrimination in the workplace.
- All future strategies and policies, developed at a regional level, whether by the PSI Working Group or others, to address the delivery of health and social services to older persons should be human rights proofed.
- Supervisory agencies and bodies - such as the Ombudsman, and the Health and Social Services Councils and regulation and inspection units charged with assessing the manner in which HPSS authorities have performed their functions in respect of older persons, should be empowered and resourced to assess the applicability of human rights principle in those agencies' activities. This approach, along with that advocated in the first recommendation above, should result in the mainstreaming of human rights principles in the delivery of health and social services to older persons.

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<sup>109</sup> Concluding Observations of the Committee on Economic, Social and Cultural Rights: United Kingdom of Great Britain and Northern Ireland, United Kingdom of Great Britain and Northern Ireland - Dependent Territories. 05/06/2002. E/C.12/1/Add.79. paragraph 11 and Concluding observations of the Committee on Economic, Social and Cultural Rights: United Kingdom of Great Britain and Northern Ireland. 04/12/97. E/C.12/1/Add.19, paragraph 22.

- Help the Aged and the Northern Ireland Human Rights Commission should lobby HPSS to provide clear benchmarks of health care, in order to gauge current standards and raise expectations.
- So that older people have access to new treatments and drugs, Help the Aged and the Northern Ireland Human Rights Commission should lobby clinical research ethical committees to ensure that older people are represented within clinical based trials.
- The Northern Ireland Human Rights Commission and Help the Aged should empower older people by making both them and their carers aware of their human rights so that they are aware when their rights are breached and can seek appropriate support.
- Further work is required by the DHSSPS to review and restructure the complaints procedures. Until this happens, HPSS should report disaggregated complaints data by age and ethnicity of complainant.
- A central point is required for older people to access relevant information about a range of services.
- The findings of the NSF Regional Audit should be formally reviewed, in light of HSSPS policies and practices in Northern Ireland. Following this, approaches could be adopted to address any direct or indirect discrimination of older people.

Clarification of the statutory human rights obligations should be outlined by service providers.

- DHSSPS and Help the Aged should request Trusts to furnish them with **all** policies that contain an age criterion so that they can review them externally. Policies, if necessary, should then be reviewed in light of clinical evidence to establish the validity for age-specific criteria.
- Section 75, Northern Ireland Act 1998 and Race Relation policies should be enforced and better efforts should be made by Trusts to ensure all staff are aware of these and comply. Everyone should be treated with dignity, respect and care, irrespective of their race or age. HPSS authorities should consider mechanisms by which relevant data could be gathered for the purposes of Section 75, if it is not already being gathered.
- Further research is required to ascertain professional and organisational discrimination of older people. The research should:
  - (a) Detail the attitudes of health professionals towards older people, their entitlement to health care and how they prioritise services.
  - (b) Investigate the methods used to rationalise services, which includes those unwritten policies of care and how this impacts on older people. Within the investigation clinical

audits of patients' care, particularly in cardiology and oncology, should be conducted so as to establish discrimination.

- The research should be conducted in conjunction with health providers, in order to achieve clearance through ethical committees and gain access to information that is not readily available to those working outside Trusts.

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## **APPENDIX A: Interview Guideline**

### **Key Issues for Research about Older People**

The research aims to uncover older peoples' experience of the health care system. Issues such as health care standards and inequalities will be focussed on.

- Physical difficulties faced by older people in gaining access to services (transport / disability)
- Access to health services – not offered / declined on the basis of age
- Information – lack of clarity, inadequacy (e.g. Awareness of roles of professionals and their own rights / entitlements)
- Infantile treatment
- Treatment – unequal, unfair, neglected, degrading  
(Nursing, GP, OT, Hospital acute, outpatient, in-patient.
- Consent to treat
- Needs of older carers

## **APPENDIX B: Interviewee Information and Consent Form**

This research about older people is being conducted on behalf of:  
Office of First Minister and Deputy First Minister  
Help the Aged  
Northern Ireland Human Rights Commission

The research aims to uncover older peoples' experience of the health care system. Issues such as health care standards and inequalities will be focussed on.

The information gained from this interview will be used within a research publication. The information YOU give will NOT be attributed to YOU

– Your name or other personal details that identify you will not be used.

THE INFORMATION GIVEN WILL BE USED ANONYMOUSLY.

You do not have to answer all questions and can retract anything you say during or after the interview by contacting the researcher.

TRANSCRIPTS AND TAPES WILL NOT BE GIVEN TO THIRD PARTIES WITHOUT YOUR CONSENT.

The limitations to anonymity are bound by the Children's NI Order (1990).

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### **Consent**

I acknowledge that the researcher has described the aims of the research and I am clear about how the information is going to be used in the final research document.

I have / have not requested the full research report when completed.

I give this information of my own free will and I am happy with the anonymity and confidentiality guidelines as set out above.

RESEARCHER: \_\_\_\_\_ Date: \_\_\_\_\_

PARTICIPANT: \_\_\_\_\_ Date \_\_\_\_\_