

LITERATURE REVIEW

EQUALITY AND HUMAN RIGHTS:

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

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INTRODUCTION

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

In 2001, the Department of Health Social Services and Public Safety (DHSSPS) commissioned a literature review which was to assist with the setting of priorities for the Department's five year Equality Impact Assessment Programme. The remit of the review was to identify, from a range of academic and other publications, significant equality of opportunity issues relating to service delivery, policy development, and implementation of, health and social services for each of the nine dimensions set out in Section 75 of the Northern Ireland Act 1998¹. The key function of the review was to summarise the information sources and findings emerging from the literature.

The outcome of the project was the publication '*Literature Review: "Equality of Opportunity" in Relation to the DHSSPS Draft Equality Scheme*², carried out by Bunting (2001), and published by the DHSSPS in March 2001. This report provided a wealth of information in regards to each of the nine dimensions set out in Section 75 and further identified a wide range of recommendations aimed at facilitating greater equity in access to health and social services in Northern Ireland.

The report justifiably acknowledges that at the time of writing, Northern Ireland-based research and information pertaining to the nine dimensions and equality of opportunity in health and personal social services, was only beginning to surface (Bunting, 2001:2). The DHSSPS recognises that significant changes have taken place since the publication of the first literature review. It has therefore deemed it necessary to commission a **follow-up** review, both to assist the Department in meeting its equality obligations and significantly, to inform the development of the new Health,

¹ Section 75 of the Northern Ireland Act 1998 places a statutory duty on all public authorities to have due regard to the need to promote equality of opportunity, between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation, between men and women generally, between persons with a disability and persons without, and, between persons with dependants and persons without.

² can be accessed from the DHSSPS website at www.dhsspsni.gov.uk/publications/2003/literature_review/literature_review.asp

Social Services and Public Safety (HPSS) **strategy and action plan to address inequalities and promote human rights**³.

Remit and Scope of the Current Review

The remit of this report is to provide a follow-up to the Bunting (2001) review. Its purpose is to provide an account of relevant literature, both academic and other publications, which have emerged since the publication of the first literature review. It will, in the first instance follow closely the remit of the first review, that is, to identify significant equality issues relating to HPSS service delivery and policy development pertaining to the nine Section 75 dimensions.

In developing its strategy and action plan to address inequalities and promote human rights, the Department intends to focus more clearly upon the difficulties experienced by service users, patients, and excluded groups in terms of **accessing health and social services**⁴. This report, therefore, primarily explores the inequities and barriers to accessing health and social services experienced by each of the Section 75 dimensions and identifies subsequent recommendations for action.

The scope of this report differs slightly from that of the first review carried out in 2001 in that, in addition to the Section 75 dimensions, it is also directed to examine:

- a) socio-economic and geographic inequalities in access to health and social services; and
- b) relevant human rights issues.

The Structure of the Report

For continuity and comparative purposes the structure of this review closely follows that of the first one. There are nine sections each corresponding to one of the Section 75 dimensions (that is, religious belief, political opinion, racial group, age, marital status, sexual orientation, gender, disability and, dependant status). Each

³ see the Equality section in the DHSSPS website for further details of the strategy - www.dhsspsni.gov.uk/equality/index.asp

⁴ DHSSPS (2004) *A Strategy and Action Plan to Address Inequalities and Promote Human Rights* - www.dhsspsni.gov.uk/publications/2004/equality_Project_Brief.pdf

section provides an account of the issues relating to equity of access to health and social services which have emerged from literature published between March 2001 and September 2004.

A growing proportion of research in more recent years has been dedicated to raising awareness of the issue of “multiple identity” (for example, Zappone, 2003). Such research has exposed the complex nature of people’s identities and reveals that an individual can have characteristics which span across many of the Section 75 dimensions.

These many different facets of identity can often interact with each other and result in quite distinctive barriers to accessing health and social services. Therefore, the choice of the Section 75 dimensions as the main organising principle for this review should not be seen as implying that these are discrete groups of people.

Identifying Publications

The literature reviewed in this report were identified using a wide range of sources including:

- electronic database searches (i.e. ORB, EBSCO, Ingenta, Sage journals);
- library catalogue searches (i.e. Queen’s University and University of Ulster catalogues, Northern Ireland Assembly Library catalogue); and,
- general internet searches (i.e. research and information contained within Northern Ireland-based university web pages; reports published by local and GB voluntary and community groups and charities; DHSSPS publications; OFMDFM publications; research published by bodies such as the King’s Fund and the Joseph Rowntree Foundation; local newspaper searches).

An effort was made to concentrate upon identifying research and other information which was Northern Ireland-based. However, GB-based literature, and in some instances international literature, has been referenced where important inferences for Northern Ireland could be drawn from the publications.

Although the search for literature was quite extensive it is not been possible to identify *all* relevant publications relating to inequity in access to health and social services. However, any access issues not captured in the literature review are expected to be picked up from the other sources used as part of the stock take phase of the project to develop the strategy and action plan.

A “Stock-take” of Equality and Human Rights Issues

A strategic audit of equality issues is considered an essential task in the development of the strategy and action plan to address inequalities and promote human rights. This literature review represents only one element of the stock-take of issues. Engagement with stakeholders and interest groups is a key feature of the strategy and action plan developmental process. The issues raised by stakeholder and interest groups will form an important part of the strategic audit of equality and human rights issues. Other key elements of the audit will include a review of the outcomes of both the Public Attitudes to Health and Personal Social Services Survey⁵ and the “Equality and Inequalities in Health and Social Care in Northern Ireland: A Statistical Overview” report.

Published by the DHSSPS in May 2004, the report “**Equality and Inequalities in Health and Social Care in Northern Ireland: A Statistical Overview**”⁶, draws together a wide range of information relating to inequalities in health and social care. Areas covered by the report include, the impact of conflict on the population’s health and well being; lifestyle; stress mental health and suicide; and, health and social care activity. The report also provides an assessment of area differences in morbidity, utilisation of, and access to, health and social care services and is the base report of the new Inequalities Monitoring System⁷.

The statistical overview report and follow up bulletin⁸ provides a wealth of comparative information between people living in rural

⁵ see “Public Attitudes to Health and Social Services in Northern Ireland – Final Report” (2004) www.dhsspsni.gov.uk/publications/2004/pas/pas-report.asp

⁶ see “Equality and Inequalities in Health and Social Care in Northern Ireland: A Statistical Overview” (2004) www.dhsspsni.gov.uk/publications/2004/equality_inequalities/equality_inequalities.asp

⁷ see “Health and Social Care Inequalities Monitoring System: First Update Bulletin” (2004) <http://www.dhsspsni.gov.uk/publications/2004/iqs-1stupdate-bulletin04.pdf>

⁸ see “Health and Social Care Inequalities Monitoring System: First Update Bulletin” (2004) <http://www.dhsspsni.gov.uk/publications/2004/iqs-1stupdate-bulletin04.pdf>

and non-rural areas, between different social classes, and between the nine Section 75 dimensions of the Northern Ireland Act 1998. Due to time constraints and the enormity of information provided in the statistical overview report it is not possible to include all its key findings within the scope of this literature review. **Therefore, it is strongly recommended that this literature review is read in conjunction with the findings of the Equality and Inequalities statistical overview report.**

Limitations of the Literature Review

It is important to acknowledge at the outset what this report *is*, what it *is not*, and what it can *realistically achieve*. To begin with, it is not an academic literature review as such. Time and resource constraints, in addition to the vast quantity of relevant equality and human rights issues do not permit it to be so. Rather the report aims to provide short synopses of issues, any one of which could be explored in much greater detail than is provided by this report. The report merely aims to draw to the attention of the DHSSPS and other relevant agencies, the vast body of literature which captures actual experiences of discrimination and unfair treatment in accessing and using health and social services, and which identifies potential and actual human rights violations.

It must be noted that this report by no means provides a definitive list of relevant equality and human rights issues in regards to access to health and social services. Again, taking into account time and resource constraints, the number of issues are so vast that it is not possible to account for them all. Additionally, by the time this report neared completion other new information and research emerged⁹ and will continue to do so. Consideration should be given to periodically updating this report to reflect any new literature, particularly that which is directly relevant to Northern Ireland. A short list of relevant websites has been enclosed at the end of each section of the report to facilitate the monitoring of any new and emerging information.

⁹ For example, an OFMDFM report on lone parent households (Scullion et al, 2005); a report on ageing and rural poverty (Rural Community Network, 2004); research commissioned by the Northern Ireland Commissioner for Children and Young People on Children's Rights in Northern Ireland which covers, amongst other issues, health, welfare and material deprivation (Kilkelly et al, 2004); the DHSSPS Public Satisfaction Survey, etc.

In reading this report, one must also consider that its remit merely covers *access to, and use of*, health and social services in terms of equality and human rights. It is not within the scope of this review to report on other important equality and human rights issues in the HPSS in Northern Ireland. It does not therefore cover inequalities in terms of health outcomes, nor does it consider the equality and human rights issues relating to employment in the health and personal social services.

This report primarily concentrates upon the experiences of services users. It is not within its remit to explore equality and human rights implications from a HPSS staff viewpoint. Although there are undeniably many important issues for staff (for example, the human rights implications of the rise in violence towards HPSS staff, the treatment of migrant workers in the HPSS, the racial abuse of black and minority ethnic staff etc). This is clearly an area which requires further research and much greater attention in its own right.

Limitations of the Review: Socio-Economic Status and Geographic Inequalities

This review does not examine socio-economic and geographic inequalities in access to health and social services in any great detail as these issues are covered extensively by the DHSSPS *“Equality and Inequalities in Health and Social Care in Northern Ireland: Statistical Overview”* Report (2004). This report does, however, provide a review of some of the recent qualitative research which explores the experiences of those living on low incomes and those in deprived rural and urban areas in terms of access to health and social services.

It is worth noting at this point that the DHSSPS Weighted Capitation Formula, used by the DHSSPS to allocate resources to the HSS Boards, is now much more sophisticated than purely area-based allocated methods and relates directly to two of the Section 75 dimensions - age and gender. The Formula recognises that needs differ even across deprived areas and takes account of factors such as population size, age profile, the higher cost of service delivery in rural areas and additional (deprivation-related) need. The Capitation Formula is regularly reviewed and is informed by an extensive programme of evidence-based research. It is recommended that, in identifying socio-economic and

geographical inequities, consideration should also be given to the Report of the Capitation Formula Review Group and its supporting research reports¹⁰.

Limitations of the Review: Human Rights

Since the Human Rights Act 1998 came into force in October 2000, it has been unlawful for any public body, including HPSS bodies and agencies, to act in a way which is incompatible with the rights enshrined in the European Convention on Human Rights (ECHR). Developing an awareness of human rights in a health and social services context is crucial for facilitating greater equity in access to services and for ensuring that both HPSS staff and service-users are treated with the dignity and respect they deserve.

During the course of the literature review it became noticeably difficult to locate Northern Ireland-specific research which made explicit connections between health and social services provision and human rights. However, it must be acknowledged that research in this area is beginning to emerge¹¹ (for example, see Northern Ireland Human Rights Commission publications) and must be continuously monitored in order to identify key issues for the HPSS.

A number of high profile cases in recent years have highlighted the importance of human rights and their impact upon medical decision-making. For example, the Human Organs Inquiry, issues around euthanasia and assisted suicide, and decisions surrounding whether to withdraw or withhold life-prolonging treatments from seriously ill children. Due to time constraints, this report does not examine such issues in any great detail nor does it provide examples of case law. The review, therefore, examines the issue of human rights in a health and social services context only on a very rudimentary level.

¹⁰ see www.dhsspsni.gov.uk/econsultation/capitation/capitation_docs.asp

¹¹ The Northern Ireland Human Rights Commission (NIHRC) have published several reports examining the issue of human rights and health care provision for a number of groups including, female prisoners; people with mental health problems and their carers and families; young lesbian, gay and bisexual people; children in custody; older people. The NIHRC have also commissioned research into sudden and unexpected deaths arising from surgical and medical interventions, an issue which is relative to Article 2 of the ECHR - www.nihrc.org/index.htm

It is recommended that further research is carried out in regards to the affect of the Human Rights Act 1998 on the HPSS in Northern Ireland. It would assist both HPSS staff and service-users, if a Human Rights (and possibly an Equality) information and knowledge-base was developed for the HPSS. The National Health Service Litigation Authority (NHSLA) have developed a “Human Rights Information Service”¹² for the NHS in England and have appointed a Human Rights Information Manager to:

- develop a database of information on how the Human Rights Act is affecting the NHS; and,
- ensure that NHS bodies are kept up to date with significant developments in health care law resulting from the Human Rights Act.

Perhaps it would be useful for the DHSSPS to explore the merits of putting into place similar structures including a centrally co-ordinated equality and human rights information base in order to raise awareness of human rights and equality issues throughout the HPSS.

Limitations of the Review: Other Issues

This review primarily concentrates upon the equality duties set out in Section 75¹³, and to a lesser extent, human rights law, in regards to access to health and social services in Northern Ireland. It is crucial to note, however, that there are a number of other relevant factors which are significant to the promotion and facilitation of equity of access to health and social services. For example, the “good relations” duty outlined in Section 75 of the Northern Ireland Act, the Disability Discrimination Act 1995¹⁴, the Race Relations (Northern Ireland) Order 1997 and the development of a single equality bill for Northern Ireland to name but a few. The Government has also signed up, and is in the process of signing up, to a number of European Directives and international treaties and conventions¹⁵ which are also relevant to

¹² see NHSLA website - <http://www.nhsla.com/HumanRights/>

¹³ of the Northern Ireland Act 1998.

¹⁴ a consultation process is currently in progress for a draft Disability Discrimination (Northern Ireland) Order to ensure that people with disabilities receive fair treatment in additional areas. See <http://www.ofmdfmi.gov.uk/disabilitydiscrimination/disability/index.htm>

¹⁵ For example, the UN Convention on the Rights of the Child and the UN Convention on the Elimination of All Forms of Discrimination Against Women.

the promotion of equality of opportunity. However, it is not within the remit of this report to examine these issues in detail.

Key Interventions for Addressing Inequalities and Human Rights

It should be noted at the outset that each section of this report is somewhat negative in tone. This is largely unavoidable given that remit of the literature review is to identify inequities and human rights issues in access to health and social services. It does not, therefore, acknowledge in any great detail the significant policy and service interventions which have, and which are currently being developed, on a number of different levels to address existing inequalities.

The “*Investing for Health*” Strategy, for example, is a major cross-departmental approach to reducing health inequalities. Other cross-departmental strategies are currently in development and include an anti-poverty strategy and strategies which specifically relate to, children and young people, older people, gender, and race equality. On a departmental level, the new twenty year Regional Strategy, the Primary Care Strategy, the Capitation Formula, and other more specific strategies and action plans¹⁶ have also been developed to tackle inequalities, including inequities in service access.

Additionally, a wide range of policy and service developments have also taken place at HSS Board, Trust, LHSCG and Agency level. Mention must also be given to the significant contribution made by HPSS staff, and the community and voluntary sectors, towards addressing many of the inequities in service access identified by this report. However, it is not within the remit of this report to assess how far these interventions are addressing the inequities identified from the literature reviewed.

Literature Review Recommendations

Each section of this report contains a wide range of recommendations aimed at facilitating greater equity in access to

¹⁶ For example, the Five Year Physical Activity Strategy and Action Plan; the Five Year Tobacco Action Plan; Home Accident Prevention Strategy and Action Plan; Mental Health Promotion Strategy and Action Plan; Drug and Alcohol Strategies etc.

health and social services. The vast majority of these recommendations have been *sourced directly* from the various research reports reviewed. This approach has been taken for a number of reasons. Firstly, the number of inequities in service access are so voluminous that it would be too time consuming for a non-expert in each area to devise suitable recommendations. Secondly, the authors of the research reports highlighted in this review have studied their subject areas in-depth and are therefore best placed to advise on appropriate service interventions.

Where possible, recommendations which specifically relate to improving access to services in Northern Ireland have been identified. However, where gaps in Northern Ireland-based literature exist, recommendations emerging from GB and international literature which are applicable to Northern Ireland, have been included.

Conceptual and Definitional Issues: “Equality”, “Equity” and “Access”

The terms “equality” and “equity” are used frequently throughout the following sections. These two concepts tend to be used interchangeably in both health and other public policy. However, it is not necessarily the case that all inequalities are inequitable (for example, disparities in health status exist due to the ageing process). The concept of “equity” is essentially about fairness and social justice and has both a moral and ethical dimension (Whitehead, 1990:5). Inequity tends to refer to, “*differences which are unnecessary and avoidable but, in addition are also considered unfair and unjust*” (Whitehead, 1990:5). An equitable service is one which offers equality of access to health care to individuals in equal need (Le Grande et al, 2003:6).

The concept of equity in health care, however, differs from country to country, and can mean different things to different people (Whitehead, 1990:15). Therefore, it is possible that many of the issues and barriers to health and social services identified in the following sections may not necessarily be deemed to be inequitable by some.

“Access” to Health and Social Services

The key objective of this review is to identify inequities in “access” to health and social services in Northern Ireland. In this context, however, it is crucial to consider that that “access” is about much more than the ability to *physically* access services. Although physical access is undoubtedly an important factor.

Arksey et al (2003:33) highlights that the concept of “access” can be disaggregated into different dimensions, each of which can be examined separately and different operational measures or interventions developed. Penchansky and Thomas (1981) cited in Arksey et al (2003:33) identify five different dimensions of “access” including:

- **accessibility** (whether service-users can physically reach the services);
- **availability** (whether service is provided);
- **accommodation** (whether the service is organised in such a way that it accommodates the needs of the service-user);
- **affordability** (whether service-users are able to pay for services); and,
- **acceptability** (whether the service is acceptable to service users).

The accessibility of health and social services is given frequent mention in this review and as such it is important to reflect upon the multi-dimensional nature of the concept of “access” whilst considering the various sections of this report.

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