



Disability programmes and policies:
 How does Northern Ireland measure up?
 Monitoring Implementation (public policy and programmes) of the United Nations Convention on the Rights of Persons with Disabilities (“UNCRPD”) in Northern Ireland.

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1. Executive Summary

1.1. Introduction

With limited exceptions, United Nations human rights treaties do not expressly address the human rights of people with disabilities. Recognition of the need for the UN to play a much greater and 'enabling' role in promoting and monitoring the rights of people with disabilities resulted in the United Nations Convention on the Rights of Persons with Disabilities coming into force on 3 May 2008 and being ratified by the UK on 8 June 2009. It contains 50 Articles and encompasses a range of civil, political, economic, social and cultural rights. The overall purpose of the Convention is to **'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'**¹

The Convention² contains a range of rights and obligations from, for example, the Right to Life (Article 10), to Education (Article 24), Health (Article 25) and Statistics and Data Collection (Article 31).

While the rights specified in the Convention are largely specified in other human rights instruments, the Convention focuses on the actions that States must take to ensure that people with disabilities enjoy these rights on an equal basis with others. To date, 101 States have ratified the Convention and there have been 149 signatories.

The Convention is a new human rights treaty and there are limited resources available to determine the exact nature and extent of obligations with respect to policies and programmes for each Article. As the interpretation of the UNCRPD by the Committee on the Rights of Persons with Disabilities develops over time, the conclusions of this study can be refined. It should also be noted that the timeframe of the study coincided with the development of the United Kingdom UNCRPD report and the continuing development of policies and programmes within the local justification.

¹ United Nation Convention on the Rights of Persons with Disabilities, (2007), Article 1

² For explanation of the full Articles of the UNCRPD please see:
<http://www.equalityni.org/archive/pdf/UNCRPDOptionalProtocolPE.pdf>

1.2. Research Remit

The Equality Commission for Northern Ireland commissioned Disability Action's Centre on Human Rights for People with Disabilities to carry out research to identify key strategic issues / barriers in public policies and programmes to the full implementation in Northern Ireland of the UNCRPD.

The main aim of this research was to identify areas of substantive shortfalls in public policy and programme delivery in Northern Ireland relative to the key requirements of Articles 5-31 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) which will influence the implementation of the UNCRPD.

The research was limited to policies and programmes and does not systematically and exhaustively consider obligations with respect to legal measures required by the Convention. It is essential that the findings of this research be considered in the light of the legal obligations on States Parties contained in the UNCRPD and the interaction of current legislation.

1.3. Methodology

The research adopted a mixed methods approach which combined: an identification of policies and programmes from the text of the Convention itself; an analysis of a small scale questionnaire (n=44) and workshop (n=28) from the Independent Mechanism for Northern Ireland, December 2010 conference and of 6 focus groups (n=67 in total) held during December 2010 to February 2011; an examination of policies, programmes and guidelines in Northern Ireland and of information from key stakeholders. A key method used in this research was the involvement of people with disabilities and their representatives in the identification and analysis of key areas and how these related to the real lives and experiences of disabled people. The information examined relates to the period July 2010 to March 2011 although some key data after that period has been included when possible.

1.4. Results

The full report identified a range of shortfalls or gaps in key programmes and policies relevant to the Articles of the UNCRPD. Using the available literature and research with disabled people, their representatives and other stakeholders, three priority or **key areas** for action fundamental to the effectiveness of any programme to fulfil the implementation, monitoring and accessibility requirements of the UNCRPD were chosen.

A '**key area**' is where a requirement or set of requirements of specific Articles of the Convention appear to be inadequately implemented to the extent where they impact on the fundamental compliance of State policy and programmes with the requirements of the UNCRPD and/or where they fulfil

one of the **Priority Criteria**³ agreed with the ECNI. Implicit in this definition is the central importance of **cross cutting Articles**⁴ and themes which impact negatively or positively on other Articles in their implementation, monitoring and accessibility to persons with a disability.

Three key areas for action were identified in the research. These three areas are not exhaustive or exclusive of others which would be of legitimate concern to people with disabilities, and are crucial to achieving the aims of the UNCRPD, notably independent living, employment and education.

1.4.1. Key Areas

The three key areas identified were **Awareness Raising** (Article 8), **Participation in Public and Political Life** (Article 29) and a combined key area of **Access to Information** (Article 9 and 21) and **Statistics and Data Collection** (Article 31). The key areas are cross cutting in that they are interrelated with effects on each other and on the full and effective realisation of all articles of the Convention.

1.4.1.1. Awareness Raising

Article 8 of the UNCRPD imparts on the State, obligations in relation to the raising of awareness regarding people with disabilities; fostering respect for the rights and dignity of persons with disabilities; combating stereotypes, prejudices and harmful practices in all areas of life, including those based on sex and age. These duties must be effective, immediate, and appropriate.

Awareness raising permeates into all aspects of the UNCRPD and the real lives of people with disabilities, from the driver on the bus thinking about stopping for a disabled person, the High Court judge giving a witness or defendant with a speech impediment extra time and the Jury not assuming they are nervous or lying, to the policy maker realising that they must speak to a group of disabled people before a policy is mapped out.

³ Priority Criteria were:

1. The issue is one of the most intractable or persistent and/or one on which little progress is being made;
2. The issue is disproportionately damaging, i.e. the group affected may be small but the impact substantial;
3. The 'direction of travel' is negative i.e. existing evidence shows a worsening experience for disabled people.

⁴ Cross cutting Articles are those Articles and obligations which have a fundamental influence on the delivery of all Articles. Good delivery on these matters will have a positive effect on the effectiveness of a wide range of Articles whereas a poor implementation will have a negative influence on Articles

The Report of the Promoting Social Inclusion Working Group on Disability⁵ also recognised the central nature of awareness raising in promoting inclusion commenting that, “Our goal is to create a culture where positive attitudes are promoted towards disabled people, one in which their needs are mainstreamed into all aspects of life and where all services are delivered on a rights basis and in an appropriate and supportive way”.

A focus group participant with disabilities summed the situation up when commenting on health services,

“They assume that we can’t think or speak for ourselves, work, have children, need contraception, or smear tests ... we can’t have a family, we have a disability, I am not a non-person, they treat us as non-persons.”⁶

The scale and scope of action required in raising awareness throughout society and the scope of the article to include awareness at the family level, is beyond that contained in the disability duties, which under the Disability Discrimination Act 1995 (DDA) applies only to public authorities. The UNCRPD duties under Article 8 will require intervention in all functions of the State and will include changing stereotypes, prejudices and harmful practices towards persons with disabilities through the media, education and attitudinal influencers such as the churches and political parties. The researchers found that while the scale of change required is recognised by some key stakeholders, clear central direction and coordination is vital. The challenge to society will be to not just incorporate the necessary changes into the current disability duties but to ensure that areas such as family attitudes and groups, for example, private sector organisations etc, which are not included in these duties, are addressed.

“Need to think bigger – national campaign – changes in schools and prisons etc – make people think, for example about access.”⁷

“Those that have been there need to be behind awareness raising.”⁸

Findings from the focus groups suggest that education and the participation of people with disabilities is the key to the required change in attitudes. An early clear directive to raise awareness of the rights of people with disabilities and address negative attitudes towards them should be provided by the State. This should be supported by information and monitored by

⁵ Office of the First Minister and deputy First Minister (OFMdFM) (2009) The Report of the Promoting Social Inclusion Working Group on Disability. OFMdFM: Belfast

⁶ Comment from participant of the Representative Scoping Focus Group on the 14/01/2011

⁷ Comment from a participant of the Service User Scoping Focus Group on the 15/12/2010

⁸ Comment from participant of the Representative Scoping Focus Group on the 14/01/2011

an inspection regime that will influence attitudes and behaviour towards disabled people within the family, classroom, workplace and wider society.

1.4.1.2. Participation in Political and Public Life

Article 29 of the UNCRPD imparts on the State obligations to ensure that persons with disabilities can effectively participate in political and public life. States Parties must actively promote an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs and encourage their participation. This is to be done without discrimination and 'on an equal basis with others'.

Throughout Article 29 there is an emphasis not only on 'full' participation, but on 'effective' participation. The obligation to ensure the latter is clearly significant in assessing the adequacy of the range of policies and programmes which aim at delivering on its obligations.

The Participatioon identification of this key area reflected the clear evidence from the focus groups that disabled people were not being asked in a comprehensive way, their opinions on policies and programmes that affect them as citizens in Northern Ireland. The evidence from the focus group emphasised the principle of 'Ask First' in which people with disabilities and their representatives must be engaged and involved at the outset of the policy making process and are not merely consulted at the end of the process.

"Ask first - 'the person with the disability knows what the disabled person needs.'"⁹

Article 29 is reinforced by the fundamental principles of "full and effective participation and inclusion in society" (Article 3), and by the general obligation "to closely consult with and actively involve persons with disabilities" in all aspects of decision-making" (Article 4). These principles contained in the UNCRPD provide one of the clearest expressions in international human rights law of the right to participate in decision-making.

Focus group participants commented on the lack of engagement between them and political parties and stressed that greater contact including outreach programs was required.

"Increase participation of disabled people in political parties and contact from political parties with disabled people and groups."¹⁰

⁹ Comment from a participant of the Representative Scoping Focus Group on the 10/01/2011

¹⁰ Comment from a participant in the Thematic Focus Group on the 26/01/2011

However the greatest concern of focus group participants was participation with the wider decision making processes. Participants commented that current consultation tended to be solely in relation to issues concerning disability and not on issues of common concern, for example on the environment. Focus group participants believed that this was not participation in political and public life as required by the UNCRPD. Disabled people and their representatives also commented that there was a lack of action coming from consultations and that there should be more consideration for the additional expenses, including transport, communication support and time required by some disabled people to participate. The group suggested a standardisation of practice and that action should be taken to resolve any identified problems.

Participants in the focus group commented that capacity building of disabled people was required in order to equip them with the skills required to fully participate including lobbying skills, information about government systems and how to access information. They suggested the increased use of participative forums and greater involvement in the decision-making process, but commented that people would only join these if they knew action was coming from them.

Evidence from the research has suggested that the establishment of a Participation Network similar to that funded by the OFMdfM for Children and Young Persons, to act as an expert interface between Government and disabled people may be beneficial in increasing effective participation of and consulting with disabled people. Participants in the focus groups stressed the requirements for meaningful participation and not merely token consultation, for example:

“Can get people to “listen” but they don’t actually hear.”¹¹

“Ignorance, assumptions, why are we not listened to?”¹²

“Assembly / Departments (to) have a forum of disabled people or a participation network that they can come to.”¹³

Significant change is required in Government practices on engagement and the provision of information if the current situation is to be improved quickly.

Whilst the situation in relation to the consultation of disabled people is concerning, it is telling that the focus groups believed that the situation will improve when the UNCRPD begins to be implemented.

¹¹ Comment from a participant in the Thematic Focus Group on the 26/01/2011

¹² Comment from a participant in the Service User Scoping Focus Group on the 15/12/2010

¹³ Comment from a participant in the Thematic Focus Group on the 19/01/2011

1.4.1.3. Statistics, Data Collection (Article 31) and Access to Information (Article 9 and 21)

“Knowledge is power!”¹⁴

Article 31, of the UNCRPD imparts on the State, obligations to ensure the gathering of information about people with disabilities, with the active involvement of people with disabilities, so that they and their representatives can better understand the barriers they experience and challenge the State to make the Convention’s rights a reality. Articles 9 and 21, are primarily concerned with ensuring that the State provides information, statistics and data in accessible formats and communicates these effectively to persons with disabilities.

The requirement for States Parties to collect disability data and statistics to facilitate UNCRPD implementation and to ensure that they are accessible is new to human rights treaties. This process forms part of the practical steps that are necessary to support reform including policy formulation and monitoring and to identify and address the barriers faced by different groups of disabled people through disaggregated data and research. The availability of robust data, information and statistics to the State, the independent monitoring body, society and crucially disabled people and their representatives is central to evidence-based policy making and to an effective monitoring process under Article 33 UNCRPD. However currently these statistics rarely provide the range of information required by the UNCRPD and/or are not generally accessible to disabled people and their representatives.

Article 31 is clear in that it is the responsibility of the State to undertake to collect appropriate information and to ensure the dissemination of statistics in a format that is accessible to persons with disabilities and others. Some studies do exist and further data continues to be gathered from sources such as the 2011 Census. This data clarifies the background in which the UNCRPD will operate, but it does not specifically support policy development and monitoring in a form required for the implementation of the UNCRPD. For example, Article 24 (Education) of the UNCRPD implies that the State measures the availability of teachers who are qualified in sign language and / or Braille. In this respect, existing methodological tools should be tested, and if necessary modified, with the aim to ensure their suitability for matters covered by the Convention.

An equally important factor is the accessibility of information. There is clear evidence that there are large areas of information which are inaccessible

¹⁴ Comment from a participant in the Thematic Focus Group on the 26/01/2011

to disabled people, see for example RNID and BDA (2009)¹⁵ and the ECN(2008)¹⁶, and it is particularly disappointing that a primary source of information, the internet, is underused by disabled people. A 2011 survey by the Office for National Statistics (ONS)¹⁷ revealed that participants who reported that they had 'ever used the internet'

A 2011 survey by the Office for National Statistics (ONS)¹⁸ revealed that participants who reported that they had 'ever used the internet' in Northern Ireland was for people with a DDA2 defined disability 46.3%, and for non disabled people 77.4%. The figures also reveal that internet usage amongst disabled people in Northern Ireland is less than the average in the UK for people with a DDA defined disability (63.8%). There are several reasons for this disparity, which are explored in the main study. However the absence of the implementation of a co-ordinated strategy involving disabled people is paramount. Participants in the focus groups reported that they had found some government websites inaccessible; problems were reported with the inability to change fonts, broken or incorrect links, no search boxes, and the inability to change colours.

Concerted co-ordinated action is required to be undertaken by the State with the participation of disabled people in order to resolve the current situation in relation to inaccessible information but good examples exist such as the Scottish Accessible Information Forum (SAIF)¹⁹.

1.5. Conclusions

The UN Convention on the Rights of Persons with Disabilities is at an early stage in its global implementation. The significance of many of its articles remains in some instances unclear. The UN Committee on the Rights of Persons with Disabilities is only beginning the process of definitively clarifying the obligations the Convention contains.

It became clear during the research that obligations with respect to policies and programmes are not 'detachable' from legal obligations. It is vital that

¹⁵ RNID and BDA (2009) 'Access to Public Services for Deaf Language users

¹⁶ ECNI (2008) 'Formal Investigation under the discrimination legislation to evaluate the accessibility of health information in Northern Ireland for people with a learning disability, June 2006 to December 2007'. See [http://www.equalityni.org/archive/pdf/FormallInvestDisability\(Full\).pdf](http://www.equalityni.org/archive/pdf/FormallInvestDisability(Full).pdf)

¹⁷ Office for National Statistics (2011) (ONS) 'Internet Access Quarterly Update 2011, Q1, May 2011, <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672> Note; The disaggregated figures for disabled people in Northern Ireland contained in the raw data for this survey were unpublished and were obtained by Disability Action from the ONS in May 2011.

¹⁸ Disability Discrimination Act (DDA)1995 as amended by the Disability Discrimination (Northern Ireland) Order 2006

¹⁹ See www.saifscotland.org.uk

the CRPD be interpreted, implemented and monitored as a whole, in the light of the connections and relations between the overlapping obligations of its different articles and underpinning principles.

Within the scope of this research it became abundantly clear just how limited the research base actually is in relation to disabled people / disability in Northern Ireland. There is a need for much more research in this area to ensure the full implementation of the Convention. If the situation of disabled people is not known with relative certainty with respect to the areas of their life covered by the Convention, then it is impossible for the UK and Northern Ireland governments to claim that their human rights are being respected and protected. Effective policy making and monitoring of the Convention at national or international level cannot take place without quality research being conducted into life situations of disabled people in Northern Ireland.

The full report considers a range of issues and while the research base is currently insufficient to ground detailed claims with respect to every single article of the CRPD, it was clear across the wide range of Articles considered that there are gaps in policies and programmes in Northern Ireland that need addressed.

Three priority areas were identified by the literature review and by disabled people and their representatives as key areas where the UNCRPD is not being fully implemented in Northern Ireland with respect to policies and programmes. These are:

- Awareness-raising;
- Participation in Political and Public Life;
- Statistics, Data Collection and Access to Information;

Urgent work by the State, in partnership with disabled people and their representatives, is required to address the identified gaps in policies and programmes, not least in these three priority areas.

2. Terms of Reference

2.1. Background

Article 33(2) of the United Nations Convention on the Rights of Persons with Disabilities (the 'UNCRPD' or CRPD) requires State Parties to establish "a framework, including one or more independent mechanisms... to promote, protect and monitor implementation of the present Convention". The Northern Ireland Human Rights Commission ('NIHRC') and the Equality Commission for Northern Ireland ('ECNI') have been jointly designated as the Independent Mechanism in Northern Ireland (hereafter 'IMNI'). States which have ratified the UNCRPD are required to submit periodic reports²⁰ to the UN Committee outlining the measures they have taken to implement the rights affirmed in the Convention (the 'state report'). The Independent Mechanism will submit separately, a parallel report (the "parallel report") that can inform the UN Committee assessment of the State Party report. In fulfilling its role, the IMNI must, amongst other duties, monitor implementation of the UNCRPD in Northern Ireland. Information will be gathered through a range of sources, including stakeholder involvement, to inform the parallel report. As part of this information gathering, the ECNI has commissioned this expert paper that will present robust evidence of any substantive shortfalls in public policy and programme²¹ delivery in Northern Ireland relative to the key requirements of the UNCRPD; highlighting any key issues / barriers to full implementation.

This report addresses policies and programmes, not legal measures which are beyond its scope. A **policy** is defined in the New Oxford Dictionary of English²² as: 'a course or principle of action adopted or proposed by a government, party, business or individual'. Policy-making has been defined as the process by which governments translate their political vision into programmes and actions to deliver 'outcomes' - desired change in the real world.²³ Policy can take a range of different forms, including non-intervention; regulation, for instance by licensing; or the encouragement

²⁰ The first UK State Report is due to be submitted to the UN Committee in June 2011, (two years after ratification of the Convention in the UK). The UK State Report will contain contributions from the jurisdictions of England, Scotland, Wales and Northern Ireland.

²¹ While the term "programmes" is potentially broad, the focus of this aspect of the expert paper should be on issues relating to public service provision / delivery. Guidance indicates that monitors should identify whether such programmes include persons with disabilities and are supportive of their rights (Ref: Office of the High Commissioner for Human Rights (2010). Monitoring the Convention on the Rights of Persons with Disabilities – Guidance for Human Rights Monitors. Professional training series no 1.

²² OFMdfm, (2003) 'A Practical Guide to Policy Making', Page 1.
See <http://www.ofmdfmi.gov.uk/policylink>

²³ Cabinet Office (1999) 'Modernising Government', White Paper

of voluntary change, including by grant aid; as well as direct public service provision.²⁴

The term **programme** is defined in the Concise Oxford Dictionary as ‘a planned series of events, a set of related measures or activities with a long term aim’.²⁵ The Advanced English Dictionary states programmes are: ‘a series of projects or services intended to meet a public need’.²⁶ In the OFMdfM document, ‘A Practical Guide to Policy Making’²⁷ the term is not defined but is used in the context of a series of actions to deliver outcomes in the real world.

The term **disability** or **persons with disabilities** is not defined within the UNCRPD. The United Nations UNCRPD website²⁸ refers to elements of the Preamble and Article 1 to provide guidance to clarify the application of the Convention:

‘Disability’ - The Preamble recognises that “disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.

‘Persons with disabilities’ - Article 1 States that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

Several elements of these provisions are relevant to highlight. First, there is recognition that ‘disability’ is an evolving concept resulting from attitudinal and environmental barriers hindering the participation of persons with disabilities in society. Consequently, the notion of ‘disability’ is not fixed and can alter, depending on the prevailing environment from society to society.

Second, disability is not considered as a medical condition, but rather as a result of the interaction between negative attitudes or an unwelcoming environment with the condition of particular persons. By dismantling attitudinal and environmental barriers - as opposed to treating persons with disabilities as problems to be fixed - those persons can participate as active members of society and enjoy the full range of their rights.

²⁴ OFMdfM, (2003) ‘A Practical Guide to Policy Making’, Page 1. See <http://www.ofmdfmi.gov.uk/policylink>

²⁵ Pearsall, J. (Ed.)(1999) ‘The Concise Oxford Dictionary’, 10th Ed.

²⁶ See <http://www.appolicious.com>

²⁷ OFMdfM, (2003) ‘A Practical Guide to Policy Making’, Page 1. See <http://www.ofmdfmi.gov.uk/policylink>

²⁸ See <http://www.un.org/disabilities/default.asp?navid=24&pid=151#sqc3>

Third, the Convention does not restrict coverage to particular persons; rather, the Convention identifies persons with long-term physical, mental, intellectual and sensory disabilities as beneficiaries under the Convention. The reference to 'includes' assures that this need not restrict the application of the Convention and States Parties could also ensure protection to others, for example, persons with short-term disabilities or who are perceived to be part of such groups.

2.1.1. Disability under the Disability Discrimination Act 1995

Within Northern Ireland the definition used by the State, public bodies and enforcement agencies is that contained in Section 1 and Schedule 1 of the Disability Discrimination Act 1995 (DDA). The definition has been the subject of several legal clarifications but can be defined as, "**A physical or mental impairment** which has a **substantial** and **long-term adverse** effect on a person's ability to carry out **normal day-to-day activities**"²⁹.

Physical or mental impairment: These include, physical impairments affecting the senses such as sight and hearing, heart disease, diabetes, epilepsy; mental impairments including learning disabilities and mental ill health.

Substantial: For an effect to be substantial, it must be more than minor. The following are examples that are likely to be considered substantial:

- inability to see moving traffic clearly enough to cross a road safely;
- inability to turn taps or knobs;
- inability to remember and relay a simple message correctly.

Long-term: These are effects that:

- have lasted at least 12 months; or
- are likely to last at least 12 months; or
- are likely to last for the rest of the life of the person affected.

Long-term effects include those which are likely to recur. For example, an effect will be considered to be long-term if it is likely both to recur, and to do so at least once beyond the 12-month period following the first occurrence.

Normal Day-to-day Activities:

Day-to-day activities are normal activities carried out by most people on a regular basis, and must involve one of the following broad categories:

- mobility - moving from place to place;

²⁹ See ECNI website for a fuller explanation. <http://www.equalityni.org/archive/pdf/DefinitionofDisability07.pdf>

- manual dexterity - for example, use of the hands, wrists or fingers;
- physical co-ordination;
- continence;
- the ability to lift, carry or move ordinary objects;
- speech, hearing or eyesight;
- memory, or ability to concentrate, learn or understand;
- being able to recognise physical danger.

As seen above there is clearly a conflict between the 'medical model' approach of the DDA and the 'social model' approach of the Convention. The social model holds that disabled people are disempowered not by their disabilities but by barriers in society. These barriers include the environment, people's attitudes and inflexible policies, practices and procedures. Under the medical model, disabled people are defined by their illness or medical condition. They are disempowered; medical diagnoses are used to regulate and control access to social benefits, housing, education, leisure and employment. The medical model promotes the view of a disabled person as dependent and needing to be cured or cared for. Control resides firmly with professionals; choices for the individual are limited to the options provided and approved by the 'helping' expert. The medical model is sometimes known as the 'individual model' because it promotes the notion that it is the individual disabled person who must adapt to the way in which society is constructed and organised.³⁰

The interpretation and implementation of the Convention and its compatibility with existing legislative provisions under the DDA framework will prove challenging to the State, courts and the monitoring systems under Article 33 until the State fully accepts the social model.

A respondent to a questionnaire carried out for this study commented that there was, **"still too much emphasis put on the medical model of disability as opposed to the social model of disability and this means that because of this, most government schemes only work for people who fit neatly into the stereotypical boxes of disability."**³¹

2.2. Aim

The aim of this paper is to present robust evidence of any substantive shortfalls in public policy and programme delivery in Northern Ireland relative to the key requirements of the UNCRPD (Articles 5-31), highlighting any key issues / barriers to full implementation.

³⁰ http://www.open.ac.uk/inclusiveteaching/pages/understanding-and_awareness/medical-model.php

³¹ Comment from a respondent to the IMNI Conference questionnaire 2010

2.3. Objectives

Implicit in the Convention are three distinct obligations of all State Parties, namely the obligations to respect, protect and fulfil the rights of persons with disabilities. Adopting the three obligations as an overarching framework, the project objectives were to:

1. Identify the key requirements of public policy and programme delivery that would fulfil UNCRPD Articles 5-31³². Having done so, then identify which key policies and programmes in Northern Ireland are most relevant to fulfilling these key requirements;
2. Identify any substantive shortfalls between public policy and programme delivery in Northern Ireland relative to the key requirements identified in objective 1; and where gaps exist, present robust evidence of the shortfall;
3. Present an assessment of any key areas of non-compatibility of public policy and programmes in Northern Ireland relative to Convention Articles 5-31, highlighting any key issues/barriers to full implementation.

2.4. Exclusions

The project is not intended to produce an exhaustive analysis or statement of compliance against a Convention which has the potential to touch on all areas of a disabled person's life. Rather it seeks to present evidence to highlight some key shortfalls between public policy and programme delivery in Northern Ireland against the requirements of this new UN human rights Convention. It is thus a non-exhaustive consideration in that it will focus on reporting any evidence of non-compatibility/shortfalls, rather than seeking to provide a 'confirmation of compliance' for each Article. The project has not included a national survey of disabled people, but incorporates the views of disabled people gathered through a series of focus groups. The project did not examine the gaps between the legal obligations of the UNCRPD and the current legislative framework applicable in Northern Ireland as this was excluded by the terms of reference. It is however considered essential that this study is examined together with a legal gap analysis, as policies and programmes are not detachable from legal obligations; in order to fully assess the environment on which positive change must take place.

In order to present evidence, as described above, it is important that as robust an analysis as possible is carried out on the obligations contained in the Convention. This analysis is necessarily provisional since the Committee on the Rights of Persons with Disabilities has yet to make formal statements

³² While mindful of the general requirements established by wider Convention articles, the study focused its attention on a consideration of Articles 5-31 inclusive.

as to its understanding of the requirements of the CRPD. The Committee has not yet issued Concluding Observations or General Comments and these will be key resources in determining the nature of the obligations the CRPD actually imposes on States Parties.

In producing the report stringent attention was paid to the actual text of the UNCRPD itself. Analysis of the UNCRPD text was based on the principles of legal interpretation and read in light of the Vienna Convention on the Law of Treaties which provides that 'a treaty shall be interpreted in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in the light of its object and purpose.'³³ The research also drew upon the Reporting Guidelines³⁴ of the Committee on the Rights of Persons with Disabilities as an authoritative statement of key requirements of State Party reporting on the denoted rights.

Given that the Committee on the Rights of Persons with Disabilities has not yet elaborated upon the meaning of the UNCRPD rights in any great detail, the research drew upon the work of other treaty monitoring bodies, where appropriate, to clarify the requirements of UNCRPD Articles 5 - 31 as they apply to public policy and programmes. In particular the project team drew upon the General Comments of the Committee on Economic, Social and Cultural Rights (CESCR), the Committee on Civil and Political Rights (CCPR), the Committee on the Rights of the Child (CRC), and the Committee on the Elimination of Discrimination Against Women (CEDAW).³⁵ One potential source of material relevant to the interpretation of the CRPD is the preparatory materials, but these are not currently available in an edited version. Currently available material may not be complete in terms of its coverage and thus could mislead interpretation. In addition, preparatory materials are a supplementary means of interpretation to be drawn upon "in order to confirm the meaning resulting from the application of Article 31, or to determine the meaning when the interpretation according to Article 31: (a) leaves the meaning ambiguous or obscure; or (b) leads to a result which is manifestly absurd or unreasonable."³⁶ For the above reasons, combined with the scope of the Project, no analysis of the preparatory materials has been conducted.

³³ Article 31, Vienna Convention on the Law of Treaties, adopted 23 May 1969, entered into force 27 Jan 1980, 1155 UNTS 331

³⁴ Committee on the Rights of Persons with Disabilities (2009), Reporting Guidelines CRPD/C/2/3

³⁵ See for example, CESCR (2000), 'General Comment No. 14 on the Right to Health', [www.unhcr.ch/tbs/doc.nsf/\(symbol\)/E.C.12.2000.4.En](http://www.unhcr.ch/tbs/doc.nsf/(symbol)/E.C.12.2000.4.En); CESCR (1991) 'General Comment No. 4 on the Right to Adequate Housing', <http://www.unhcr.ch/tbs/doc.nsf/0/469f4d91a9378221c12563ed0053547e?Opendocument>; CCPR (1992) 'General Comment 20 relating to the prohibition of torture, cruel, inhuman or degrading treatment', <http://www.unhcr.org/refworld/docid/453883fb0.html>.

³⁶ Article 32, Vienna Convention on the Law of Treaties, adopted 23 May 1969, entered into force 27 Jan 1980, 1155 UNTS 331.

From the sources indicated above, an Article by Article analysis was produced setting out the substantive requirements of Articles 5-31 of the UNCRPD. The project has not tried to develop human rights indicators. However the analysis which has been conducted will be useful for the development of indicators or to provide a basis for further analysis in greater depth.

Obligations in the CRPD are sometimes requirements to address disability issues specifically in general policies and programmes, rather than requiring disability-specific policies and programmes. Such obligations are often expressed as requiring disabled people to be treated 'on an equal basis with others' and thus implicitly refer to the obligations contained in other human rights treaties.³⁷ In many respects, the CRPD 'rests' on existing human rights obligations and the explication of its obligations must be in the light of the obligations of the other treaties. It is beyond the scope of this project to conduct an analysis of how the obligations of the **other** UN human rights treaties apply to persons with disabilities.³⁸

³⁷ in particular the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights

³⁸ For an analysis of how disability issues have been approached by other treaty bodies, see Quinn G., & Degener T., (2002) 'Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability', (New York/Geneva: United Nations).

3. Background to UNCRPD

The formal identification of people with disabilities as subjects with rights rather than as burdensome 'objects' or 'problems', is recent. With limited exceptions, the core UN human rights treaties have not expressly addressed the human rights of people with disabilities.³⁹ Recognition of the need for the UN to play a much greater and 'enabling' role in monitoring the rights of people with disabilities gained increasing prominence in the 1990s and in a 1993 report it was observed that other groups had the benefit of thematic conventions while disabled people did not.⁴⁰ In 2001, the General Assembly issued a resolution on a 'Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities'.⁴¹ This resolution noted that "despite different efforts made to increase cooperation and integration, and increasing disability awareness and sensitivity to disability issues..., these efforts have not been sufficient to promote full and effective participation and opportunities for persons with disabilities in economic, social, cultural and political life." Coupled with the legal unenforceability of existing declarations, this set the wheels in motion for a disability specific convention.

The United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted by the General Assembly of the United Nations on 13 December 2006. It opened for signature on 30 March 2007 and came into force on 3 May 2008, 30 days after ratification by Ecuador, the 20th State. To date, 101 States have ratified the Convention and there have been 149 signatories.⁴² As the first UN human rights treaty of the 21st century, the CRPD "brings into play a different way of seeing the reality of the lives of people with disabilities, a different set of values with which to judge existing social arrangements and wholly new policy prescriptions to

³⁹ Only the Convention on the Rights of the Child contains explicit references to disability while other human rights treaties have subsumed disability under '...other status', as demonstrated in Article 2(1) of the International Covenant on Civil and Political Rights (1966) and Article 2(2) of the International Covenant on Economic, Social and Cultural Rights. Article 2 of the CRC prohibits discrimination in the enjoyment of the Convention rights on the grounds of disability. Article 23 of the CRC specifically addresses the rights of children with disabilities to, inter alia, enjoy a 'full and decent life' (art.23(1)) and to 'special care' (art.23(2)).

⁴⁰ Despouy, L. (1993) Human Rights and Disabled Persons, UN publication No.E.92.XIV.4. Para 280/281. Despouy was appointed Special Rapporteur by the Sub-Commission on Prevention of Discrimination and Protection of Minorities.

⁴¹ G.A. Res 56/168 2001.

⁴² As of 03 June 2011. Both the UK and Ireland signed the Convention at the first opportunity on 30 March 2007. The UK ratified on 8 June 2009. The Optional Protocol also came into force on 3 May 2008 and the UK ratified the Protocol on 7 August 2009.

bring about improvements.”⁴³ The first textual explication of both adults and children with disabilities in an international human rights treaty, the CRPD has been variously hailed as ‘ground breaking’⁴⁴, ‘historic and path breaking’⁴⁵, as the ‘dawn of a new era’⁴⁶, and as constituting a ‘paradigm shift’ away from a medicalised approach to disability towards one that is firmly located in rights discourse.⁴⁷ Of particular significance is the transparency and unprecedented level of engagement by civil society in the negotiation process. Civil society in this context largely encompassed organisations **of** people with disabilities as opposed to organisations **for** people with disabilities. The consequence of such a high level of civil society engagement is reflected in the final treaty provisions. The Convention thus represents a historic break from a State-centric model of treaty negotiation “towards a participatory approach that takes the views and lived experience of the affected as the principal point of departure.”⁴⁸

The CRPD is structured in a typical fashion. It comprises 50 Articles and encompasses a full range of civil, political, economic, social and cultural rights. As such, its overall purpose is to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.’ The treaty begins with a series of introductory (Preamble) and interpretive Articles (Articles 1 and 2); continues with general obligations (Articles 3 to 9) and substantive rights (Articles 10 to 30), and establishes implementation and monitoring processes (Articles 31 to 40). It also sets out the rules which govern the operation of the Convention such as how States become party and when it will come into force (Articles 41 to 50). Through the Optional Protocol, an individual complaints procedure is established, allowing individuals and groups of individuals to raise complaints with the treaty body where they have exhausted domestic and regional remedies. It also

⁴³ Quinn, G. (2008) ‘Resisting the ‘Temptation of Elegance’: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?’ In O.M. Arnardottir and G. Quinn (eds) *The UN Convention on the Rights of Persons with Disabilities*, Leiden: Martinus Nijhoff Publishers, pp.215-278, at p.216.).

⁴⁴ Waddington, L. (2008) ‘Breaking New Ground: The Implications of Ratification of the UN Convention on the Rights of Persons with Disabilities for the European Community’, in O.M. Arnardottir and G. Quinn (eds) *The UN Convention on the Rights of Persons with Disabilities*, Leiden: Martinus Nijhoff Publishers, pp.111-140, at p.111.

⁴⁵ Melish, T.J. (2007) ‘The UN Disability Convention: Historic Process, Strong Prospects, and Why the U.S. should ratify’, *Human Rights Brief*, 14(2), pp 37-47, at p.37.

⁴⁶ Official Statement of the UN Secretary General: ‘Secretary General hails adoption of landmark Convention on the Rights of Persons with Disabilities’, 13 December 2006, SG/SM 10797, HR/4911.

⁴⁷ Ambassador Don McKay, Chair of the Ad Hoc Committee, (2007) ‘From Vision to Action: The Road to Implementation of the Convention on the Rights of Persons with Disabilities.’ Speech delivered at the signature ceremony, 30 March 2007.

⁴⁸ Melish, T.J. (2007) ‘The UN Disability Convention: Historic Process, Strong Prospects, and Why the U.S. should ratify’, *Human Rights Brief*, 14(2), pp 37-47, at p.4.

establishes an inquiry procedure in relation to gross or systematic violations of the rights contained in the Convention. While the rights specified in the Convention are largely specified in other human rights instruments, the Convention focuses on the actions that States must take to ensure that people with disabilities enjoy these rights on an equal basis with others.

3.1. Treaty Interpretation and the UN Convention on the Rights of Persons with Disabilities⁴⁹

The decentralised nature of international law means that, in general terms, States are left to 'auto-interpret' the law; more often than not, in their own favour.⁵⁰ As with a number of other human rights treaties, where the Convention on the Rights of Persons with Disabilities is concerned, auto-interpretation has been tempered by an independent third-party in the guise of a Committee. This Committee makes suggestions and general comments or recommendations on giving effect to the provisions of a treaty. In this manner, the Committee on the Rights of Persons with Disabilities provides, as a result of its make-up (its Members being of "high moral standing and recognised competence and experience in the field covered by the present Convention") an authoritative interpretation of the Convention on the Rights of Persons with Disabilities. Thus, while any one State may seek to provide an interpretation of the Convention, the Committee is best placed to give the authoritative expression of the manner in which the Convention should be interpreted. The Reporting Guidelines developed by the Committee and any Concluding Observations issued are thus important sources of information as to what policies and programmes might be required by the Convention.

The Committee on the Rights of Persons with Disabilities will, in seeking to interpret the Convention on the Rights of Persons with Disabilities, look to the rules of interpretation of international law to assist States in giving effect to the provisions of the Convention. Section 3 of the 1969 Vienna Convention on the Law of Treaties sets out the general rules of treaty interpretation and it is within these parameters that the provisions of the Convention on the Rights of Persons with Disabilities are to be understood.

It should be emphasised that the International Law Commission, in drafting the provisions of interpretation which appear in the Vienna Convention considered that these should be read not in a formalistic manner, but

⁴⁹ This section draws heavily on research completed for Disability Action's Centre on Human Rights by Dr Jean Allain of the School of Law, Queen's University Belfast; Allain, J (2008) Legal Position of Reservations to the UN Convention on the Rights of Persons with Disabilities, Legal Report 1, (Centre on Human Rights, Disability Action; 2008); Allain, J, (2009) Treaty Interpretation and the UN Convention on the Rights of Persons with Disabilities, Legal Report 2, (Centre on Human Rights, Disability Action; 2009).

⁵⁰ See Leo Gross, (1984) "States as Organs of International Law and the Problem of Auto-interpretation", Essays on International Law and Organizations, Vol. 1, 1984, pp. 367-397.

holistically. While there is an inherent logic to treaty interpretation, the International Law Commission considered that the various elements in any given case should be “thrown into a crucible, and their interaction would give the legally relevant interpretation”.⁵¹ Article 31 of the Vienna Convention sets out the general rule of treaty interpretation as follows and the ‘crucible’ approach mandates that weight be given to each of these four elements thus “allowing them to work together”.⁵² A treaty is to be interpreted:

1. **In Good Faith:** central to effective international relations is that States are to act in good faith. This notion is translated into the fundamental principle of treaty law: *pacta sunt servanda*, which is spelled out in Article 26 of the Vienna Conventions as “every treaty in force is binding upon the parties to it and must be performed by them in good faith”.
2. With regard to its **Ordinary Meaning:** in interpreting a treaty one should not seek to read into the text what is not there. That words or phrases, as an original drafter of the Vienna Convention has noted, “are to be given their normal, natural, and unstrained meaning”.⁵³
3. **In Context:** a word or phrase is not to be read in isolation but in reference to the section it finds itself in, as well as the overall treaty including its preamble and any annexes; thus mandating that a treaty be interpreted as a whole.
4. **In Light of the Object and Purpose:** emphasis here is to give effect to what the treaty is meant to achieve. This teleological approach gives more weight to the intentions of the negotiators than the specific wording of the text.⁵⁴

In seeking to interpret a treaty, a consideration in good faith of the ordinary meaning of a provision would be considered a textual reading of a convention; amounting to what, on paper, the UNCRPD says. This should be considered the fundamental pillar of interpretation.

Where ‘in context’ is concerned, it should be understood that when an Article consists of more than one paragraph - where, for instance such paragraphs are separated into alpha- or numerical sub-paragraphs - there is a requirement to read and interpret the Article as a whole. Thus for instance,

⁵¹ As quoted in Gardiner, R. (2008) *Treaty Interpretation*, p. 9.

⁵² Gardiner, R.(2008). *Treaty Interpretation*,pp. 37-38.

⁵³ Sir Gerald Fitzmaurice, International Law Commission Rapporteur on the Law of Treaties, as reproduced in Malgosia Fitzmaurice, “The Practical Working of the Law of Treaties”, Malcolm Evans (eds) *International Law*, 2006, p. 198.

⁵⁴ Article 31(1) of the Vienna Convention on the Law of Treaties reads: “A treaty shall be interpreted in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in the light of its object and purpose”.

with regard to Article 33 of the UNCRPD on National Implementation and Monitoring, Sub-paragraph (1) related with establishing a governmental focal point for implementation, would need to be considered in relation to sub-paragraph (2) related to establishing an independent mechanism to monitor implementation. Both of these sub-paragraphs would also have to be read in conjunction with the obligation of Article 33(3) which requires that “Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process”.

That said, the requirement to interpret a treaty ‘in context’ creates a unique situation where the UNCRPD is concerned. Interpreting ‘in context’ requires that one read the specific provision in light of the overall treaty. Where the UNCRPD is concerned, its unique character mandates an approach which turns to the ‘object and purpose’ as these are given voice, in part, through Article 3 which set out the Convention’s ‘General Principles’.

Article 3 - General Principles

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

This is so as Article 3 read in conjunction with Article 4, which sets out ‘General Obligations’ wherein the Convention establishes that “States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability”, establishes the object of the UNCRPD.

Article 4 - General Obligations

- 1 States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:
 - (a) To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
 - (b) To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
 - (c) To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
 - (d) To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
 - (e) To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;
 - (f) To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;
 - (g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;

- (h) To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;
 - (i) To promote the training of professionals and staff working with persons with disabilities in the rights recognised in the present Convention so as to better provide the assistance and services guaranteed by those rights.
- 2 With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.
- 3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.
- 4 Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.
- 5 The provisions of the present Convention shall extend to all parts of federal States without any limitations or exceptions.

The Convention also makes plain its purpose as Article 1, which states:

‘The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.’

Thus, with regard to the UNCRPD, the negotiating States sought to give voice to a reading of the Convention which interprets the treaty in the light of its object and purpose by requiring a reader of the Convention to, after having taken into consideration the ordinary meaning of the a word or phrase, to move directly to consider via Articles 1, 3, and 4, the ‘object and purpose’ as contextualising one’s interpretation, that is as reading the text ‘in context’.

As a result, the overall emphasis of interpretation where the Convention on the Rights of Persons with Disabilities is concerned is different than previous UN human rights treaties. An interpretation of this Convention, must continuously have recourse to the aim of fulfilling the purpose of “promoting, protecting and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promoting respect for their inherent dignity”; with a look to the general principles of Article 3 and general obligation of Article 4 as setting out the object of the Convention.

Turning to further rules of treaty interpretation, the general rules of treaty interpretation as set out in the Vienna Convention also require, beyond the provisions of a treaty, the taking into consideration of “any subsequent agreement between the parties” as to interpretation and “any subsequent practice in the application of the treaty”. Where the UNCRPD is concerned, subsequent practice may be manifest in the body of law and general recommendations set down by the Committee on the Rights of Persons with Disabilities.

If, in utilising these general rules of treaty interpretation, the meaning of a provision of a treaty is left “ambiguous or obscure”, or “leads to a result which is manifestly absurd or unreasonable”, Article 32 of the Vienna Convention allows for recourse, as “a supplementary means of interpretation”, consideration of the legislative history of the treaty (the so-called; travaux préparatoires), that is: “the preparatory work of the treaty and the circumstances of its conclusion”.⁵⁵

⁵⁵ Where the Convention on the Rights of Persons with Disabilities is concerned, the travaux préparatoires were developed by the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities and is available at: <http://www.un.org/esa/socdev/enable/rights/adhoccom.htm>

⁵⁶ See Committee of Economic, Social and Cultural Rights,(1990) ‘The Nature of States Parties Obligations’, General Comment 3, 14 December 1990, para. 1.

3.2. Obligations flowing from Economic, Social and Cultural Rights

The UNCRPD maintains the distinction which is found within the International Covenants wherein civil and political rights have obligations which are to be given immediate effect; while certain economic, social and cultural rights are to be progressively realised. Article 4 (2) speaks to this distinction:

“With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.”

It is only certain provisions of the International Covenant on Economic, Social and Cultural Rights which allow for the possibility of progressive realisation, it having been noted by the Committee on Economic, Social and Cultural Rights (CESCR), that the Covenant: “also imposes various obligations which are of immediate effect”¹, not least of which are related to issues of discrimination. Thus, any policies or programmes required by Articles of the Convention which relate to ESC rights are not necessarily subject to progressive realisation.

Within the UNCRPD, reference to economic, social and cultural rights should be understood as being applicable to elements of Articles:

- 24: Education;
- 25: Health;
- 26: Habilitation and Rehabilitation;
- 27: Work and Employment;
- 28: Adequate Standard of Living and Social Protection;
- 30: Participation in cultural Life, Recreation, Leisure and Sport.

It should be emphasised that it is only certain elements of these Articles which will be allowed to be realisable in a progressive manner. For instance, Article 25 - Health, may allow State Parties to the UNCRPD to provide “the right to the enjoyment of the highest attainable standard of health” to “the maximum of its available resources” with a view to achieving this right progressively, moving toward the full realisation of these rights. Yet there is very little else in that Article which can be deemed to be progressively realisable. With immediate effect, State Parties to the UNCRPD must ensure that “the right to the enjoyment of the highest attainable standard of health” is provided “without discrimination on the basis of disability”. As a result, the requirement to “provide persons with disabilities with the same range, quality and standard of free or affordable health care”; the providing of “those health services needed by persons with disabilities specifically

because of their disabilities”; the requirement of health professionals to provide care of the same quality to persons with disabilities”; the prohibitions of discrimination in the provision of health insurance; and the prevention of “discriminatory denial of health care or health services or food and fluids on the basis of disability” will be placed upon State Parties with immediate effect.

The UNCRPD contains the obligation “to take measures to the maximum of its available resources [...] with a view to achieving progressively the full realization of these rights”. To understand what is required by States Parties of such an obligation, one should turn to the General Comment Number 3 of the CESCR, which states that the nature of such obligations is to act “within a reasonably short time” after a State becomes party to - in the case at hand - the UNCRPD, by taking measures towards the goal of full realisation of the economic, social and cultural rights and that such “steps should be deliberate, concrete and targeted as clearly as possible with the aim of moving towards meeting the obligation recognised”.⁵⁷

Reference should also be made to General Comment Number 5 of the Committee on Economic, Social and Cultural Rights which is entitled: ‘Persons with Disabilities’. That General Comment, though it predates the UNCRPD by more than a decade, provides some detail as to the obligations flowing from specific rights established by the Covenant Economic, Social and Cultural Rights which are, in turn, reproduced in the Convention on the Rights of Persons with Disabilities.⁵⁸

3.3. Prescribed Obligations

The UNCRPD is unique as a human rights treaty in the manner in which it prescribes the obligations which States Parties are to undertake. Those obligations, in general terms, are spelled out in Article 4, but are then given voice thorough the provisions of the Convention. While leaving it to States to take ‘appropriate measures’ (which include legal measures), the Convention calls on States Parties to:

- **Mainstream protection and promotion** (Art. 4(1)(c) - General Obligation); Obligation to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes.
- **Train personnel** ((Arts. 4(1)(i) – General Obligation; 9(1)(c) - Accessibility; 13(1) - Access to Justice; 20 (c) - Personal Mobility; 24(4) - Education; 25(d) - Health; and 26(2) - Habilitation and Rehabilitation);

⁵⁷ See Committee of Economic, Social and Cultural Rights, (1990) The Nature of States Parties Obligations, General Comment 3, 14 December 1990, para. 2. Emphasis added.

⁵⁸ Committee of Economic, Social and Cultural Rights, (1994) Persons with Disabilities, General Comment 5, 9 December 1994.

- **Provide specific services and/or assistance** ((Arts. 4(1)(h) - General Obligation); 7(3) - Children with Disabilities; 9(1) and 9(2)(e and f) - Accessibility; 16(2 and 4) - Freedom from Exploitation, Violence and Abuse; 19(b) - Living Independently and Being included in the Community; 20(b) - Personal Mobility; 21(c) - Freedom of Expression and Opinion, and Access to Information; 23(2) - Respect for Home and the Family; 25 - Health; 26 - Habilitation and Rehabilitation; 27(1)(e) - Work and Employment; 28(2) (a and c) - Adequate Standard of Living and Social Protection; 29(a)(iii) - Participation in Political and Public Life; 30(1)(c) and (5) (e) - Participation in cultural Life, Recreation, Leisure and Sport; and 32(1)(d) - International Cooperation);
- **Consult persons with disabilities, including children with disabilities and their representative organisations** (Art. 33(3) National Implementation and monitoring, 4(3) General Obligations, and Participation in political and public life 29(a) and 29(b);
- **Develop effective awareness campaigns** (Art. 8(2)(a) - Awareness-Raising);
- **Modify infrastructures** (Art. 9(1)(a) - Accessibility); employ certain skilled personnel (Art. 24(4) - Education);
- **Involve persons with disabilities and their representative organisations in monitoring** (Art. 33(3) - National Implementation and Monitoring).

The UNCRPD is thus relatively detailed in terms of what it requires State Parties to do. The list of obligations above is indicative of the kinds of obligations with respect to policies and programmes that are required by the CRPD.

3.4. Affirmation of rights

The Convention on the Rights of Persons with Disabilities affirms a number of rights already recognised through established human rights instruments, including:

- The Right to Life (Art. 10);
- Equality Before the Law (Art. 12);
- Liberty and Security of the Person (Art. 14);
- Freedom from Torture (Art. 15);
- Freedom of Movement (Art. 18);
- Freedom of Expression (Art. 21);
- Right to Privacy (Art. 22);
- Education (Art. 24);
- Health (Art. 25);

- Housing (Art. 26);
- Work (Art. 27);
- Adequate Standard of Living (Art. 28);
- Political Participation (Art. 29).

The CRPD assists the reader in being able to identify pre-existing rights by utilising the terms ‘reaffirm’ or ‘recognize’, such as in Article 12 (“States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law”) or Article 25 (“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”).

The affirmation of rights is a clear articulation that these rights are applicable to persons with disability. Where guidance may be sought as to the interpretation of these rights reference may be made to the pronouncements of the Human Rights Committee (HRC) of the International Covenant on Civil and Political Rights and the CESCR of the International Covenant on Economic, Social and Cultural Rights as a means of assisting in interpreting the like-provisions found in the CRPD. For instance, the CESCR has developed General Comments on education, health, and housing; while the HRC has General Comments on the right to life, torture, liberty, freedom of expression, freedom of movement, and privacy.⁵⁹ Further, reference may be made to monitoring bodies of the Convention on the Elimination all forms of Racial Discrimination and the Convention on the Elimination all forms of Discrimination Against Women and their pronouncements as to like provisions of the CRPD dealing with equality and non-discrimination (Arts. 5 - 7) or specific rights which include equality clauses such as Article 28(1) which reads:

“States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability”.

It might also be worthwhile to recall, when interpreting the provisions of the CRPD ‘in context’, that non-discrimination is a general principle of the Convention as noted in Article 3(b). The relationship between particular articles of the CRPD and particular articles of other human rights treaties is thus significant in terms of identifying requirements with respect to policies and programmes.

⁵⁹ For the International Covenant on Economic, Social and Cultural Rights, see General Comments 7 and 11-14; for the International Covenant on Civil and Political Rights see General Comments 6, 8, 10, 16, 20, 27,

3.5. Common Specific Phrases Recurring Within The CRPD

3.5.1. 'Appropriate measures'

The nature of the requirement of States Parties to take 'appropriate measures' has not been definitively articulated in international human rights law. Some clarification of the meaning of the term 'appropriate' as it applies to the obligations of States Parties can, however, be ascertained from the commentary of the Committee on Economic, Social and Cultural Rights.⁶⁰ It is likely that the latter's approach will form the basis of the approach that will be taken by the Committee on the Rights of Persons with Disabilities.

Whilst 'appropriate' measures are generally taken to include legislative measures, the Committee on Economic, Social and Cultural Rights has made clear that this is by no means exhaustive of the obligations of States Parties. Rather, "the phrase 'by all appropriate means' must be given its full and natural meaning."⁶¹ Thus, each State Party must decide for itself which and what type of measures are the most appropriate under the circumstances with respect to each of the rights contained in the treaty, in this context the CRPD. The Committee, in its commentary, does not merely require however, that the State Party decide for itself the 'appropriateness' of the measure chosen in demonstrating the measures that have been taken, but also the basis on which they are considered to be the most 'appropriate' under the circumstances of the State Party. However, ultimately, it remains the decision of the relevant Committee to decide, in the process of examining periodic reports, whether all appropriate measures have indeed been taken.

Among the measures which might be considered appropriate, in addition to legislation, is the provision of judicial remedies with respect to rights which may, in accordance with the national legal system, be considered justiciable. The Committee notes, for example, that the enjoyment of the rights recognised, without discrimination, will often be appropriately promoted, in part, through the provision of judicial or other effective remedies.⁶² Other measures which may also be considered 'appropriate' include, but are not limited to, administrative, financial, educational and social measures.⁶³ Similarly the Human Rights Committee, in General Comment 18, has stipulated that it is for States Parties to determine 'appropriate' measures to implement the relevant provisions. However, the Committee is to be informed about the nature of such measures and how they conform with the right in question.⁶⁴

⁶⁰ Committee on Economic, Social and Cultural Rights, General Comment 3 (1990) The nature of states parties obligations. E/1991/23

⁶¹ Ibid at para 4.

⁶² Ibid at para 5.

⁶³ Ibid at para 6.

⁶⁴ Human Rights Committee, General Comment 18 (1989) at [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/3888b0541f8501c9c12563ed004b8d0e?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/3888b0541f8501c9c12563ed004b8d0e?Opendocument) , para 4.

3.5.2. On an equal basis with others'

'On an equal basis with others' provides a benchmark for assessing what is required by a particular article of the CRPD in terms of outcome; this outcome then requires a range of policies and programmes to ensure the realisation of this outcome. This phrase essentially functions as a 'levelling' obligation, requiring States Parties to ensure that persons with disabilities are treated as well as persons without disabilities when it comes to their human rights. As such, the detail of the policies and programmes required is largely determined by the content of the obligations of other human rights treaties, not those of the CRPD. It is thus not to meet this obligation if people with disabilities are treated 'on an equal basis with others' through being treated as badly as non-disabled people.

The obligation to treat people with disabilities 'on an equal basis with others' can be found in the following places:

- Preamble
- Article 1: Purpose
- Article 2: Definitions
- Article 6: Women with Disabilities
- Article 7: Children with Disabilities
- Article 9: Accessibility
- Article 10: Right to Life
- Article 12: Equal Recognition before the Law
- Article 13: Access to Justice
- Article 14: Liberty and Security of Person
- Article 15: Freedom from torture, cruel or inhuman and degrading treatment
- Article 17: Protecting the Integrity of the Person
- Article 18: Liberty of Movement and Nationality
- Article 19: Living Independently and being included in the community
- Article 21: Freedom of Expression and Opinion and Access to Information
- Article 22: Respect for Privacy
- Article 23: Respect for Home and Family
- Article 24: Education
- Article 27: Work and Employment
- Article 29: Participation in Public and Political Life
- Article 30: Participation in Cultural Life, Leisure, Recreation and Sport

4. Methodology

4.1. General

The timeframe of the project was September 2010 to April 2011. Disability Action was contracted by the Equality Commission for Northern Ireland to undertake the work following an open tender competition.

The project consisted of three main stages:

4.2. Stage 1: The process of identification of obligations with respect to policies and programmes (6/9/2010 to 13/10/10)

The CRPD remains a relatively new human rights treaty and there are limited resources available to determine the exact nature and extent of obligations with respect to policies and programmes for each Article. As the jurisprudence of the Committee on the Rights of Persons with Disabilities develops over time, the conclusions of this report can be refined. Two key sources for identifying policies and programmes obligations will emerge over time; general comments from the Committee on particular articles and issues and Concluding Observations on particular State Reports but as yet neither is available.

In identifying requirements with respect to policies and programmes, the following steps were therefore taken, but any conclusions based on this method are somewhat provisional:

- Identification of policies and programmes from the text of the CRPD itself;
- Consideration of the obligations articulated in General Comments of other Treaty Bodies;
- Consideration of the Reporting Guidelines of the Committee on the Rights of Persons with Disabilities;⁶⁵
- Consideration in the light of the UK Concluding Observations from other Treaty Bodies;
- Consideration in the light of the content of any State Reports submitted to the Committee on the Rights of Persons with Disabilities;
- Consideration in the light of the content of any Shadow Reports submitted to the Committee on the Rights of Persons with Disabilities;
- Consideration in the light of the content of any Concluding Observations from the Committee on the Rights of Persons with Disabilities;
- Consideration in light of academic literature on CRPD.

⁶⁵ These Guidelines can be found at: <http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD-C-2-3.pdf>

With respect to many of the articles, no useful information was garnered from these sources in identifying in concrete terms the obligations with respect to policies and programmes specific to Northern Ireland although useful data was gathered in relation to the policies and programmes required in general terms. The core of interpretation of obligations with respect to policies and programmes is based on the analysis of the text of the Convention itself supplemented by the observations and conclusions on other Conventions.

The review of the last UK Concluding Observations from Other Treaty Bodies looked at the:

- Committee on Economic, Social and Cultural Rights - UK Concluding Observations (2009);
- Committee on the Rights of the Child - UK Concluding Observations (2008);
- Committee on the Elimination of Discrimination against Women - UK Concluding Observations (2008);
- Human Rights Committee - UK Concluding Observations (2008);
- Committee Against Torture - UK Concluding Observations (2006);
- Committee on the Elimination of Racial Discrimination - UK Concluding Observations (2003).

The review of the content of any State Report submitted to the Committee on the Rights of Persons with Disabilities was limited due to the international monitoring process only starting to get underway. Only State Reports that were submitted to the Committee on the Rights of Persons with Disabilities by the end date of the research were looked at. Fourteen State Reports were found, but only seven of these reports were available in English.

The State Reports available in English and analysed for State Party views as to obligations with respect to policies and programmes are:

- Australia;
- Austria;
- China (Hong Kong);
- China (Macao);
- Hungary;
- Spain; and
- Tunisia.

Those unavailable in English and thus not analysed for State Party views as to obligations with respect to policies and programmes are:

- Argentina;
- Azerbaijan;
- China;
- El Salvador;
- Paraguay;
- Peru; and
- Sweden.

Only the Shadow Reports that have actually been submitted to the Committee on the Rights of Persons with Disabilities and are thus available on the CRPD website were analysed. These included CERMI⁶⁶ (Spain), International Disability Alliance (Tunisia) and the Atlas Council (Tunisia).

In considering the nature of the obligations contained in the CRPD with respect to policies and programmes, some of the Reports which have been submitted by other State Parties were examined. This was as part of the interpretation of the obligations of the CRPD, but these reports proved to be of limited value in establishing the content of the obligations contained in each article. They nevertheless provide a glimpse into the thinking of State Parties other than the UK on the kinds of policies and programmes required by the Convention. The Reports from State Parties to the Committee are reports “on measures taken to give effect to its obligations under the present Convention” (Article 35 CRPD). The inclusion of a particular measure in a State Report thus means that it can be taken that the State concerned considers that policy or programme to be giving effect to a CRPD obligation. The Report is a means to demonstrate the State is fulfilling its obligations. However, different States will carry out their obligations in different ways - there is not one way of approaching the obligations, especially when it comes to policies and programmes (rather than law reform for instance). The examples provided from the other State Reports are thus not to be taken as requirements of specific policies or programmes which the UK is obliged to have, nor as examples of good practice which the UK is obliged to follow.

No Concluding Observations have as yet been issued by the Committee on the Rights of Persons with Disabilities.

A list of the academic literature on the CRPD which has been considered is included in this Report. The literature remains extremely generic, without detailed argument as to the content of the obligations of particular Articles. It has proven of little value for the project.

⁶⁶ Comité Español de Representantes de Personas con Discapacidad

4.3. Stage 2: Identification of shortfalls in policy and programmes in Northern Ireland (13/9/2010 to 26/11/10)⁶⁷

The research team examined the policy and programmes in Northern Ireland with relevance to the UNCRPD by desktop research using information publically available; information from contact with government departments and agencies; information from key stakeholders in the voluntary sector; and enquiries with stakeholders in academia over a 2 month period in the Autumn and Winter of 2010, although significant policies or information subsequent to this period have been included where available during the write up phase.

Following the project brief and the time and resources available, this study is not a full examination of all policies and programmes in Northern Ireland. Such a task is outside the capacity of this study and would have included policies and programmes at a national level, Northern Ireland specific measures, local policies at Board and Trust level and policies at individual schools, prisons and hospitals. This study did examine key issues within policies and programmes in Northern Ireland and proposes key areas for action to make the UNCRPD a significant force in influencing government to deliver positive outcomes for disabled people.

Significant difficulties in the completion of stage two were experienced due to an absence of summary papers and evaluation reports in policy areas, inaccessible information, a lack of disaggregated data, and a lack of a designated system or focal point by which information on disability could quickly be obtained. Some areas of government were unable or unwilling to engage with this research during the completion of the UNCRPD Northern Ireland report which was completed and submitted to the Office for Disability Issues (ODI) in February 2011 although it remains unpublished at the time of writing (April 2011). The research would suggest that these difficulties are in themselves significant for the inclusion of people with disabilities and their representative and campaigning groups in the monitoring systems required under Article 33(3). This will be discussed in the sections under access to information and statistics and data collection.

4.3.1. Disability Action member groups

The views of the Disability Action member organisations on the impact of the UNCRPD and significant policy areas were sought by means of a personal e-mail to CEOs, however a very low response rate was obtained (3 formal responses out of 133 groups within the 4 week period for response) although many of the groups took part in the focus groups in stage 3.

This low response rate is not unusual as a similar exercise with a web questionnaire by the ODI also elicited few responses.

⁶⁷ Note: While this was the timeframe allocated for this section, crucial documents, policies and programmes issued after this date have been included where possible.

Personal contact with the groups revealed that awareness of the UNCRPD at the time of the request was poor, notably amongst smaller groups. Whether this was due to time, resources or a lack of accessible information is unknown. The IMNI website and literature was available from the Summer / Autumn of 2010 and the first Conference on the UNCRPD was held by the Joint Equality Commission for Northern Ireland and Northern Ireland Human Rights Commission on the 1st December 2010 (the '2010 Conference').⁶⁸ The question of knowledge of the UNCRPD was explored in a small questionnaire study (n=44) carried out for the 2010 Conference targeting people attending the conference or browsing the relevant section of the IMNI and Disability Action websites (full details in Appendix 1) which found that 40% (n=12) knew nothing or a little about the UNCRPD. These findings resulted in the addition of information sessions in Stage 3.

4.4. Stage 3: Identification of shortfalls in policy and programmes in Northern Ireland

The findings of Stage 1 were examined against the policies and programmes identified in Stage 2 to identify shortfalls in policy and programmes in Northern Ireland.

During this process attention was paid to the results and comments from the questionnaire and the workshop carried out for the Joint Equality Commission for Northern Ireland and Northern Ireland Human Rights Commission conference on the UNCRPD and the three scoping focus groups which were held in Disability Action, Belfast during December 2010 and January 2011 to gather the views and priorities of voluntary and statutory sector representatives and disabled people.

4.4.1. December 2010 conference questionnaire

A questionnaire was designed by Disability Action staff and tested by persons with disabilities to ensure robustness (see Appendix 5). A questionnaire web link was sent by ECNI conference staff to the 156 people registered for the conference.

On the day of the conference, additional hard copies were made available to IMNI Conference staff for distribution at registration and a verbal reminder was issued during the Disability Action focus group session. A reminder e-mail was sent by ECNI to registered persons after the conference with the closure date for the questionnaire on the 10 December 2010. In total the questionnaire was open for 20 days. Alternative formats of the questionnaire

⁶⁸ Making the Disability Convention rights a reality in Northern Ireland - Have your say'. Joint Equality Commission for Northern Ireland and Northern Ireland Human Rights Commission event. 1st December 2010, Hilton Hotel, Templepatrick

were available on request however no requests for these were received by Disability Action staff

Of the 44 questionnaires returned, 24 were from the 157 registered conference delegates, a return rate of 15.2%. The average rate for response for questionnaires is approximately 20% although this varies with the target audience. For example the Disability Rights Commission Hate Crime survey⁶⁹ reported response rates from 56% to 9% dependent on the component part of the target population. Response rates are also dependent on factors such as the length of questionnaire and whether incentives are offered. No incentives were offered in this survey.

The target population for this survey was not homogenous and included elected representatives, persons with a range of disabilities, academics, voluntary sector representatives, carers, public sector representatives and people browsing the IMNI and Disability Action sections at the conference.

The number of responses was increased by an additional 20 responses, 16 of which were from unregistered persons and 4 declined to state their registration status.

The sample is self selective in that they have chosen to attend a disability conference, or to respond to a request to complete a questionnaire on the conference website. They are therefore more likely to be interested in disability issues; have access to a computer; and the ability to use it. It was also noted that no requests were received to supply questionnaires in alternative formats such as Easy Read or Braille. Taking these matters under consideration it is suggested that while the sample will not be representative of the wider community it did serve as a scoping group to examine the issues involved and suggest areas for further exploration by the more targeted focus groups.

Significance testing was not carried out on the results due to the small sample size involved. Any relevant themes and suggested conclusions were explored further in the focus groups.

The results from the questionnaire are contained in Appendix 1 and are referred to in the report where appropriate.

4.4.2. Conference workshop 'Independent Mechanism research - Priorities for public policy and programmes: Your views?'

The workshop was organised by the IMNI as part of the Conference to examine gaps in current policies and the requirements of the UNCRPD.

⁶⁹ Disability Rights Commission (2004) 'Hate Crime against disabled people in Scotland', DRC:UK

The twenty eight people who attended the workshop from the State and voluntary sectors, and people with disabilities were randomly divided into four groups.

The workshop consisted of a short explanatory presentation followed by a 20 minute discussion period during which the groups considered 3 questions, as detailed below;

Groups 1 and 2: What do you think are the 3 main gaps between the policies and programmes in Northern Ireland and the requirements of the UNCRPD?

Group 3: What are the three key barriers to people with disabilities fully participating in society in Northern Ireland?

Group 4: What policy or programme would you like to see introduced to help implement the UNCRPD in Northern Ireland?

A report from the workshop is contained in Appendix 2 and can be found on the ECNI website.⁷⁰

4.4.3. Scoping focus groups Disability Action December 2010 – January 2011

As previously reported it was observed during stage 2 of the research that awareness / knowledge of the UNCRPD was poor amongst disabled people and representatives. As a consequence, two information sessions were offered (one in December 2010 and one in January 2011) before the Stage 3 focus groups took place. Twenty two people attended these half day sessions which contained an overview of the research to date and a summary of the UNCRPD. Throughout the series of focus groups, all supportive requirements were fulfilled to enable all people with disabilities to attend and fully participate. Transport costs were paid to those who attended in a private capacity.

Details of the Disability Action scoping focus groups are as follows:

- People with disabilities scoping focus group (n= 8) on the 15/12/2010;
- Representative scoping focus group (n=9) on the 10/01/2011;
- Representative scoping focus group (n=8) on the 14/01/2011.

Each session lasted for 3 hours and notification of the focus groups was widely advertised by personal contact, by the Disability Action membership group and via the Disability Action Ezine and website. In excess of 1000

⁷⁰ See http://www.equalityni.org/sections/default.asp?secid=6&cms=Policy_UNCRPD_platform+event&cmsid=89_733_816&id=816

people personally received information about the focus groups. All focus groups were oversubscribed and places were allocated to achieve a range of demographics, including gender, type of disability, representation from large and small organisations, public services, geographical location and to include groups outside the mainstream disability representation including campaigning groups on sexuality and ethnicity. The researchers were pleased to note the wide range of people who attended the focus groups including many who have not taken part in previous discussions.

4.5. Stage 4: Assessment of key areas of non compatibility of public policy and programmes in Northern Ireland with respect to Article 5-31 of the UNCRPD

The 3 scoping focus group results and the data from the questionnaire and the conference workshop were considered with the results from the Stage 1 and 2 and the stage 3 analysis to propose 3 key areas for further investigation using the rationale from the terms of reference from the study and cross cutting measures.

The Terms of Reference for this project set out Prioritisation Criteria as examples of the criteria to be considered when assessing any key strategic issues / barriers to the full implementation of the Convention.

These were:

1. The issue is one of the most intractable or persistent and/or one on which little progress is being made;
2. The issue is disproportionately damaging, i.e. the group affected may be small but the impact substantial;
3. The 'direction of travel' is negative i.e. existing evidence shows a worsening experience for disabled people.

These mirrored the criteria used by the ODI and it is useful to retain this framework to ensure fit with the national comments on the implementation of the UNCRPD. That being said, the working definition of a key area has been defined in the project as:

A **'key area'** is where a requirement or set of requirements of specific articles of the Convention appear to be inadequately implemented to the extent where they impact on the fundamental compliance of State policy and programmes with the requirements of the UNCRPD and/or where they fulfil one of the Priority Criteria set out in the ECNI, Terms of Reference (TOR) page 6⁷¹. Implicit in this definition is the central importance of cross cutting

⁷¹ See http://www.equalityni.org/archive/Research%20docs/ToR_UNCRDP_v1-Final_090710_amended.pdf, Page 6

articles and themes which impact negatively or positively on other articles in their implementation, monitoring and accessibility to persons with a disability.

'Cross cutting articles' are those articles and obligations⁷² which have a fundamental influence on the delivery of all articles. Good delivery on these matters will have a positive effect on the effectiveness of a wide range of articles whereas a poor implementation will have a negative influence on articles.

It should be noted that this research is not arguing that there are only 3 key areas, an argument can be made for many more areas which are crucial to achieving the aims of the UNCRPD, notably independent living, employment and education. Nor is it arguing that one barrier preventing a disabled person from achieving a full realisation of their human rights and fundamental freedoms is more important than another. This research considered a range of issues through a literature review and through discussions with disabled people and voluntary sector and State organisations and the research suggests that the 3 chosen areas are fundamental to the effectiveness of any programme to fulfil the requirements of the UNCRPD.

The results of these focus groups are detailed in Appendix 3 and are used throughout this report.

4.5.1. Key areas (thematic) focus groups

Following an analysis of the questionnaire results, the comments made at the Conference workshop and the three scoping focus group with representatives from the voluntary and public sectors and persons with disabilities, three key areas of interest were identified. These areas were examined in greater depth via three focus groups (one on each area) held during January and February 2011. Participants were drawn from a mix of representatives from the public and voluntary sector and persons with disabilities. As in the scoping focus groups, each group was oversubscribed and places were allocated to achieve a range of demographic factors and reflect a wide range of disabilities. Care was exercised to ensure the full participation of all members. The thematic focus groups were larger than the scoping focus groups and this did raise some practical difficulties and these are discussed further in Appendix 4.

The focus groups consisted of a short summary presentation of the area for discussion and current policies and practices in Northern Ireland and then a facilitated discussion amongst the participants of their experiences and knowledge, priorities and proposal for positive change.

⁷² See Paragraph 3.3

These sessions reflecting the 3 identified themes were held on the following 3 dates in Jan/Feb 2011 in Disability Action Belfast: These were as follows:

- Mixed focus group (n=14) on awareness raising on the 19th January 2011;
- Mixed focus group (n=14) on participation in political and public life on the 26th January 2011;
- Mixed focus group (n=14) on access to information and statistics and data collection on the 18th February 2011.
- The results of these focus groups are detailed in Appendix 4 and are used throughout this report.

4.6. Stage 5 Analysis and write up phase (March to May 2011)

Stage 5 involved the analysis and write up phase of the project. Appendices 1 to 4 contain the results obtained.

Unfortunately the small number of respondents for the conference questionnaire precluded a statistical analysis although it did suggest areas for further study.

5. Key requirements of Articles 5 to 31 UNCRPD and key policy and programmes in Northern Ireland

This section examines the key requirements of Articles 5 to 31 of the UNCRPD subject to the caveats concerning interpretation in Section 2.4 It also examines some of the key policy areas in Northern Ireland relating to these articles.

As previously reported in Section 2.4, it is important when considering these Articles to reflect that the UNCRPD is at an early stage in its global implementation. The significance of many of its articles remains in some instances unclear. The UN Committee on the Rights of Persons with Disabilities is only beginning the process of definitively clarifying the obligations the Convention contains. It became clear during the research that obligations with respect to policies and programmes are not 'detachable' from legal obligations. It is vital that the UNCRPD be interpreted, implemented and monitored as a whole, in the light of the connections and relations between the overlapping obligations of its different articles and underpinning principles.

This research observed just how limited and piecemeal the research base actually is in relation to disabled people / disability in Northern Ireland. There is a need for much more coordinated research in this area to ensure the full implementation of the Convention. If the situation of disabled people is not known with relative certainty with respect to the areas of their life covered by the Convention, then it is impossible for the UK and Northern Ireland governments to claim that their human rights are being respected and protected. Effective policy making and monitoring of the Convention at national or international level cannot take place without quality research being conducted into the life situations of disabled people in Northern Ireland. It should also be noted that the timeframe of the study coincided with the development of the United Kingdom UNCRPD report and the continuing development of policies and programmes within the local jurisdiction.

In areas where there was an absence of evaluation evidence or Government planning information, the research focused on the knowledge and experiences of disabled people, their representatives and the front line service providers and policy makers as indicators of potential policy/programme gaps.

In practice the major social problems confronting individuals with a disability and Government alike do not come neatly sub-divided. Within the UNCRPD many articles are interconnected and exert influence on other articles which in turn influence the policy and programmes required to achieve their requirements. This is also true of government policy in which policy actions on one area of life impact on many others.

The comments below are based on the requirements of the articles they are grouped under, but the influences on the requirements are not exclusively that of the articles.

As previously commented⁷³ 'cross cutting' articles are those which have a fundamental influence on the delivery of all articles. Good delivery on these articles will have a positive effect on the effectiveness of a wide range of articles whereas a poor implementation will have a negative influence on articles.

The OFMdfM policy guidance while recognising the need for cross cutting outcomes which add value, recognises that the need to achieve cross-cutting outcomes presents a major challenge to policy-makers.⁷⁴ Actions of one Northern Ireland department can have a major impact on others. Co-ordination is key, and in the context of Article 33 (1) UNCRPD this falls within the remit of the OFMdfM.

Some clarification of the current position of the OFMdfM Disability Unit was gained on the 25th February 2011. It was commented that the OFMdfM strategic plan in the general areas of disability was to produce an Executive Response to the PSI Working Group Report on Disability, produce a PSI Strategy on Disability and produce a PSI Action Plan on Disability. All these reports will be subject to public consultation⁷⁵. This strategy would suggest that the OFMdfM is developing a living document which is responsive to need, containing a high level coordinating strategy which will involve disabled people and their representatives at a fundamental level.

This local based strategy is reflective of the UK response to the United Nations Convention on the Rights of the Child (UNCRC) in which it was commented by the UK Government that 'while our strategies are grounded in shared principles, their detail varies across the UK's nations, reflecting our commitment to genuine devolution to meet local needs.' This devolution of planning resulted in the OFMdfM Strategy, Our Children and Young People - Our Pledge: A Ten Year Strategy for Children and Young People in Northern Ireland 2006-2016.⁷⁶ It would appear from the ODI draft report that a similar 10 year strategy is planned by the OFMdfM for the UNCRPD.

Caution is however advised on using the PSI report solely as the basis for the OFMdfM plan for the implementation of the UNCRPD as not all the rights contained in the Convention were covered. Secondly due to the length of time for the report to be finalised (five years) and the absence of response since its publication in December 2009, much has changed with respect to policies and programmes and the information and statistics on which the report was based. It is suggested that a review of the PSI report is required, taking into account these changes, and that the missing rights under the UNCRPD be examined.

⁷³ Methodology Section 4.5

⁷⁴ OFMdfM, (2003) 'A Practical Guide to Policy Making', Page 16. <http://www.ofmdfmi.gov.uk/policylink>

⁷⁵ Correspondence from OFMdfM Disability Unit 25/2/11

⁷⁶ <http://www.dardni.gov.uk/index/rural-development/nirdp2007-2013/rural-development-programme-governments-cross-cutting-strategies/rural-development-programme-our-children-and-young-people.htm>

5.1. Article 5: Equality and Non-Discrimination

Article 5 - Equality and Non-Discrimination

- 1 States Parties recognise that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
- 2 States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
- 3 In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
- 4 Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 5 is essentially about the obligation of the State Party to ensure legal equality for persons with disabilities and to protect them from discrimination through making it unlawful.

However, 5 (3) places an obligation to take 'all appropriate steps' to ensure that 'reasonable accommodation' is provided.⁷⁷ There is no limitation on such steps being legal measures solely. Thus the fulfilment of Article 5 (3) requires policies and programmes as 'appropriate steps' to ensure that 'reasonable accommodation' is provided and these 'steps' could include the kinds of measures indicated in Article 9 (a) to (h). Without a range of policies and programmes, in addition to legal measures, designed to ensure that reasonable accommodation is provided, a State Party is unlikely to be fulfilling its obligation under Article 5(3). The policies and programmes required will be highly specific to the situation within particular States.

Article 5(4) is significant in that it does not **require** certain policies and programmes, but rather **permits** certain kinds of policies and programmes. Policies and programmes (as 'specific measures') are not discrimination in terms of the UNCRPD if they are **necessary** to accelerate or achieve the de facto equality of persons with disabilities.

⁷⁷ 'Reasonable accommodation' is defined in article 2 as: "...necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms."

5.1.1. Consideration of other UN human rights treaties

The right to equality and non-discrimination is a feature of most human rights instruments, most notably Article 2(1) International Covenant on Civil and Political Rights (ICCPR) and Article 2(2) International Covenant on Economic, Social and Cultural Rights (ICESCR). The Human Rights Committee has asserted that non-discrimination, together with equality before the law and equal protection of the law without any discrimination, constitute a basic and general principle relating to the protection of human rights. However, the enjoyment of rights and freedoms on an equal footing does not mean identical treatment in every instance.⁷⁸ The Human Rights Committee has emphasised that the principle of equality sometimes requires States Parties to take affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination prohibited by the Covenant. For example, in a State where the general conditions of a certain part of the population prevent or impair their enjoyment of human rights, the State should take specific action to correct those conditions. Such action may involve granting for a time to the part of the population concerned certain preferential treatment in specific matters as compared with the rest of the population. However, as long as such action is needed to correct discrimination, it is a case of legitimate differentiation under the Covenant.⁷⁹ Moreover, not every differentiation of treatment will constitute discrimination, if the criteria for such differentiation are reasonable and objective and if the aim is to achieve a purpose which is legitimate under the Covenant.⁸⁰

Similarly, the Committee on Economic, Social and Cultural Rights argues that in order to eliminate substantive discrimination, States parties be required to adopt special measures to attenuate or suppress conditions that perpetuate discrimination. Such measures are legitimate to the extent that they represent reasonable, objective and proportional means to redress de facto discrimination and are discontinued when substantive equality has been sustainably achieved. Such positive measures may exceptionally, however, need to be of a permanent nature, such as interpretation services for linguistic minorities and reasonable accommodation of persons with sensory impairments in accessing health care facilities.⁸¹ The Committee on Economic, Social and Cultural Rights has called upon States Parties to ensure that strategies, policies, and plans of action are in place and implemented in order to address both formal and substantive discrimination by public and private actors. Such policies, plans and strategies should address all groups

⁷⁸ Human Rights Committee (1989) General Comment No.18 'Non Discrimination', at para 8.

⁷⁹ Human Rights Committee (1989) General Comment No.18 'Non Discrimination', at para 10.

⁸⁰ Human Rights Committee (1989) General Comment No.18 'Non Discrimination', at para 13.

⁸¹ Committee on Economic, Social and Cultural Rights (2009) General Comment 20: 'Non discrimination in Economic, Social and Cultural Rights', at para 9.

distinguished by prohibited grounds and States Parties are encouraged, amongst other possible steps, to adopt temporary special measures in order to accelerate the achievement of equality. Economic policies, such as budgetary allocations and measures to stimulate economic growth, should pay attention to the need to guarantee the effective enjoyment of the Covenant rights without discrimination. Public and private institutions should be required to develop plans of action to address non-discrimination and the State should conduct human rights education and training programmes for public officials and make such training available to judges and candidates for judicial appointments. Teaching on the principles of equality and non-discrimination should be integrated in formal and non-formal inclusive and multicultural education, with a view to dismantling notions of superiority or inferiority based on prohibited grounds and to promote dialogue and tolerance between different groups in society. States Parties should also adopt appropriate preventive measures to avoid the emergence of new marginalised groups.⁸²

In addition, States Parties must adopt an active approach to eliminating systemic discrimination and segregation in practice. Tackling such discrimination will usually require a comprehensive approach with a range of laws, policies and programmes, including temporary special measures. The Committee on Economic, Social and Cultural Rights has called on States Parties to consider using incentives to encourage public and private actors to change their attitudes and behaviour in relation to individuals and groups of individuals facing systemic discrimination, or penalise them in case of non-compliance. Public leadership and programmes to raise awareness about systemic discrimination and the adoption of strict measures against incitement to discrimination are often necessary.⁸³

It is clear from the established jurisprudence of both the Human Rights Committee and the Committee on Economic, Social and Cultural Rights, that special measures, including adoption of policies and programmes, are permissible in order to secure genuine equality and non-discrimination with respect to groups such as persons with disabilities. The exact nature of such policies and programmes is only determinable in the light of the particular situation of a State Party.

⁸² Committee on Economic, Social and Cultural Rights (2009) General Comment 20: 'Non discrimination in Economic, Social and Cultural Rights', at para 38.

⁸³ Committee on Economic, Social and Cultural Rights (2009) General Comment 20: 'Non discrimination in Economic, Social and Cultural Rights', at para 39.

5.1.2. Comments from the Committee on the Rights of Persons with Disabilities

The Committee on the Rights of Persons with Disabilities has made it clear that with respect to Article 5 it expects States Parties to report on:

“Policies and programmes, including affirmative action measures, to achieve the de facto equality of persons with disabilities, taking into account their diversity.”⁸⁴

The Committee thus clearly interprets Article 5 as requiring policies and programmes, including affirmative action measures. This is an approach to the obligations of this article which is solidly grounded in existing international human rights law.

5.1.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other State Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

With respect to Article 5, the State Parties who have submitted reports to the Committee have focused on legal measures, rather than on policies or programmes. It is often not clear from the State Reports themselves whether policies and programmes flow from the legal measures which are described.

Austria has attempted to fulfil its obligations under Article 5 of the UNCRPD through a stage plan for federal buildings to reduce construction-related barriers to accessibility, setting up agreements with the aim of improving barrier-free access to doctor’s surgeries, stage plans for transport, providing support and alternative forms of accommodation, and ensuring that all programmes of the Austrian Broadcasting Corporation follow a number of non-discriminatory programming principles.⁸⁵ Austria thus clearly interprets the Article 5 as requiring a broad range of policies and programmes aimed at securing non-discrimination.

With respect to Hong Kong, **China** has not specified policies and programmes with respect to Article 5. With respect to Macao, Article 5(d) of

⁸⁴ Guidelines on treaty-specific document to be submitted by states parties under article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities

⁸⁵ CRPD/C/AUT/1, ‘Report to the Committee on the Rights of Persons with Disabilities: Austria’ (2 November 2010), at para 10.

the Decree-Law 33/99/M determines that discrimination must be eliminated and that policies should be progressively put in place to ensure the physical environment, social and health services, education, work, cultural and social life are fully accessible to all.⁸⁶ It is thus clearly the view of China that a wide range of policies are required by Article 5.

In Tunisia legislation has adopted the principle of positive discrimination by adopting special incentive measures that are aimed to ensure true equality of opportunity and treatment for persons with disabilities. Consequently, a quota system has been set up that ensures that a certain proportion of training and employment opportunities are allocated to persons with disabilities and that they are able to undertake private projects, obtain loans, have designated parking spaces and transportation entitlements.⁸⁷

The shadow reports submitted to the Committee on the Rights of Persons with Disabilities with respect to Spain and Tunisia do not provide interpretations as to the policy and programme obligations of Article 5.

5.1.4. Key policies and programmes in Northern Ireland relevant to Article 5

Article 5 is essentially about the obligation of the State Party to ensure legal equality for persons with disabilities and to protect them from discrimination through making it unlawful. The Article influences the interpretation of the other articles of the Convention in ensuring equality and the non discriminatory impact of any measures taken. In the absence of interpretation or comment from the UNCRPD Committee, some potential examples of these influences have been suggested by other UN instruments. An example of this is the integration of teaching on the principles of equality and non-discrimination into formal and non-formal inclusive and multicultural education. This has been undertaken with a view to dismantling notions of superiority or inferiority based on prohibited grounds and to promote dialogue and tolerance between different groups in society. States parties should also adopt appropriate preventive measures to avoid the emergence of new marginalised groups.⁸⁸

States Parties must also adopt an active approach to eliminating systemic discrimination and segregation in practice. Tackling such discrimination will usually require a comprehensive approach with a range of laws, policies and programmes, including temporary special measures. Policy in relation to this Article stems mainly from the duties under the DDA and DDO and

⁸⁶ CRPD/C/CHN/1/ADD.2, 'Report to the Committee on the Rights of Persons with Disabilities: Macao' (30 August 2010), at para 20.

⁸⁷ CRPD/C/TUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Tunisia' (14 July 2010), at para 47.

⁸⁸ Committee on Economic, Social and Cultural Rights (2009), at para 38.

comprehensive guidance is provided on these matters by the ECNI amongst others. However it also affects a number of areas including education, health and accessibility policy.

Some areas of concern with respect to Northern Ireland are as follows:

5.1.4.1. Volunteering

There is no law and linked policy prohibiting discrimination in relation to volunteering. At the moment 21% of the Northern Ireland population have a disability, only 5% of whom are involved in volunteering.⁸⁹ This figure is considerably less than in GB with figures of 13%⁹⁰ to 19%⁹¹. The Promoting Social Inclusion (PSI) Report recognised the importance of volunteering to disabled people when it commented that volunteering and mentoring are additional non-qualification based forms of learning that merit particular consideration.⁹² This is linked to Article 27 UNCRPD 'Work and Employment', as it is an entry path for disabled people to gain experience and enter the workforce. The PSI Report recommended that people with disabilities should be supported to pursue volunteering opportunities through the provision of financial assistance with equipment, travel and communication.

The DSD issued a public consultation paper in 2009 on volunteering 'Join In, Get Involved: Build a Better Future - A Consultation Paper on a Volunteering Strategy for Northern Ireland'⁹³ which recognised that disabled people are under-represented in volunteering and that particular barriers exist in relation to access to information and insurance cover. It was also noted that at present organisations wishing to provide reasonable adjustments for volunteers with disabilities have to fund these adjustments themselves.

Schemes exist, such as the Department for Employment and Learning's Access to Work, which are available to provide support for people looking for paid work opportunities. However there are currently no similar schemes for volunteers.

Contact with the DSD revealed that a new volunteering strategy is being formulated and will be made available shortly. Embedded in this new strategy will be an action plan to encourage and facilitate people with disabilities to become involved in volunteering.⁹⁴

⁸⁹ DSD (2009) 'Join In, Get Involved: Build a Better Future – A Consultation Paper on a Volunteering Strategy for Northern Ireland'. DSD July 2009

⁹⁰ Home Office, (2006) 'British Crime Survey'

⁹¹ Williams B., et al (2008) 'Experiences and Expectations of Disabled People', ODI 2008

⁹² OFMdFM (2009) 'Report of the Promoting Social Inclusion Working Group on Disability', 2009

⁹³ DSD (2009) 'Join In, Get Involved: Build a Better Future – A Consultation Paper on a Volunteering Strategy for Northern Ireland'. DSD July 2009/2009

⁹⁴ Conversations with the DRD during January 2011

Positive action to promote and facilitate volunteering through policies and programmes can reasonably be seen as an obligation of Article 5 in the context of Northern Ireland.

5.1.4.2. Insurance

Insurance (individual rather than group) is in part covered by the DDA. It is recognised that there is a need for insurers to be allowed to distinguish between individuals when they are carrying out their “risk assessment”. However, it is up to the insurer to prove that there is an additional risk associated with a disabled person arising from their disability. The DDA Code of Practice states that blanket assumptions should be avoided. The Association of British Insurers in its ‘Guide to the DDA for Life and Disability Insurers’⁹⁵, makes the same point when it advises its members that;

‘You should never rely on assumptions, stereotypes or generalisations about disabled people. All your decisions must be based on relevant information or data available at the time which will form the basis of your underwriting manual’.⁹⁶

The guide comments that under the goods and services section of the DDA, there are only a limited number of circumstances when service providers may offer disabled people less favourable treatment. The guide comments that ‘less favourable treatment is justified only if, in your opinion, one or more of the following conditions are satisfied and it is reasonable for you to hold that opinion’.⁹⁷ The conditions are:

- ‘The treatment is necessary in order not to endanger the health or safety of any person (which may include that of the disabled person).
- The disabled person is incapable of entering into an enforceable agreement, or of giving an informed consent, and for that reason the treatment is reasonable in that case. This does not apply if the disabled person is represented under a Power of Attorney.
- In relation to refusing to provide a service, the treatment is necessary because the provider of services would otherwise be unable to provide the service to members of the public.
- In relation to either the standard of the service provided or the terms on which the service is provided, the treatment is necessary in order for the provider of services to be able to provide the service to the disabled person or to other members of the public.

⁹⁵ Association of British Insurers (2003) A Life and Disability Insurer’s Guide to the Disability Discrimination Act 1995, Page 14

⁹⁶ Ibid

⁹⁷ Ibid

- In relation to the terms on which the service is provided, the difference in the terms reflects the greater cost to the provider of services in providing the service to the disabled person'.⁹⁸

However, this does not apply to reasonable adjustments, for example, the provision of documents in alternative formats such as large print or in Braille.

The guide reports that less favourable treatment by an insurer when providing services will only be deemed to be justified if all of the following conditions are satisfied:

- It is in connection with insurance business carried on by the service provider;
- It is based on information which is relevant to assessment of the risk to be insured, for example, a medical diagnosis or statistical data;
- The information is from a source on which it is reasonable to rely, e.g. a medical report from the individual's GP or consultant;
- The less favourable treatment is reasonable having regard to the information relied on and any other factors (e.g. a medical report; medical history).⁹⁹

The insurers guide further comments that, 'you can use other information provided it is relevant, current and from a source on which it is reasonable for you to rely. As the DDA does not define 'reasonable', you must adopt a commonsense approach until precedents have been set through test cases'.¹⁰⁰

The researchers are not aware of any challenge to the current structure and the concept of 'reasonableness' in this context. It is currently possible to deny insurance or apply high premiums which are unaffordable for many disabled people if the current conditions described above are satisfied.

Article 5 UNCRPD must be read in conjunction with Article 25(e) which expressly prohibits discrimination against persons with disabilities in the provision of health insurance and life assurance where life insurance is permitted by national law, which shall be provided in a fair and reasonable manner. The question is one of fairness and reasonableness. A policy which discriminates against persons with disabilities without strong lawful justification, under the principles of fairness and reasonableness with respect to health and life insurance is clearly in breach of the obligations of Article 5.

⁹⁹ Ibid

¹⁰⁰ Association of British Insurers (2003) 'A Life and Disability Insurer's Guide to the Disability Discrimination Act 1995', Page 15

The matter is specifically discussed in the final draft EU Council Directive 2008/0140¹⁰¹ which as of May 2011 still awaits approval by the EU and its comments must therefore be treated with caution.

The draft EU Directive comments that the Commission has received many complaints about discrimination in the insurance (and banking sector). It comments that 'the use of age or disability by insurers and banks to assess the risk profiles of customers does not necessarily represent discrimination: it depends on the product. The Commission will initiate a dialogue with the insurance and banking industry together with other relevant stakeholders to achieve a better common understanding of the areas where age or disability are relevant factors for the design and pricing of the products offered in these sectors'.¹⁰² It is proposed that, 'six years after the adoption of the directive, the governments of the Member States and the national equality bodies send the Commission information for a report to the EU parliament and Council on the application of the directive. This report may make proposals to revise and update the directive'.¹⁰³

Discussion **before change** is implemented is always welcome and the views of persons with disabilities and their representative organisations must be central to this. As the EU Draft document acknowledges, it has received a number of complaints about insurance practices. However, the human rights framework has changed since the UNCPRD has been ratified by the EU and 14 member states including the UK (as of May 2011, all member states have signed it). It would, therefore, be useful to examine the nature of these complaints and consider the implications and the evolving legal framework before the acceptance of the draft directive. Which NI Department would lead on a local discussion is unclear and this may fall to the OFMdfM to initiate and insure the full participation of persons with disability and their representatives. It is recommended that this discussion begins now in order to influence both local arrangements and national and EU processes and discussions.

The draft Directive also comments that a special rule has been added under Article 2 'Concept of Discrimination' for the insurance and banking services, 'in recognition of the fact that age and disability can be an essential element of the assessment of risk for certain products, and therefore of price. The draft directive further comments that, 'If insurers are not allowed to take age and disability into account at all, the additional costs will have to be

¹⁰¹ EU Council (2008) Final Draft Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation; See; <http://www.europarl.europa.eu/oeil/OpenDetailFiche.do?ficheld=1544&language=en>

¹⁰² Ibid Paragraph 2

¹⁰³ EU Commission, Civil Liberties, Justice and Home Affairs (2008) Commission's Impact Assessment Document number SEC (2008)2180

entirely borne by the rest of the “pool” of those insured, which would result in higher overall costs and lower availability of cover for consumers. The use of age and disability in the assessment of risk must be based on accurate data and statistics¹⁰⁴. This article in the draft directive if passed unchanged may be suitable for challenge on a number of fronts. Firstly it may be in conflict with the EU Charter of Fundamental Rights¹⁰⁵ (see the case below in relation to gender); secondly, the arrangements may not fulfil the fairness and reasonableness requirements of UNCRPD Article 25(e) or, finally, the requirement to keep accurate statistics is not met.

It may be some time before the Directive is passed by the EU due to continuing objections by a number of countries and the changing legislative, human rights and policy environment. As stated above, the EU has ratified the UNCRPD (on the 23rd December 2010) however the ratification of the Optional Protocol¹⁰⁶ of the UNCRPD is still pending.

The council has adopted a decision on the 26 November 2009 allowing the EU to conclude the Convention which will enter into force only after adoption, by the EU Council, of a code of conduct and the submission of an instrument of formal confirmation at the UN. The Commission has called on the Council to decide rapidly on the required Code of Conduct and on the remaining Member States to speed up their national ratification procedures.¹⁰⁷

Pending EU movement on the draft directive and local and national discussion taking place it may be that legal challenges in the national courts using the anti discrimination articles of the UNCRPD may progress the matter.

Some support may be gained on this matter from the European Court of Justice 2009 case which examined whether it was compatible with the fundamental rights of the European Union to take the sex of the insured person into account as a risk factor in the formulation of private insurance contracts (primary ruling) taking into consideration provisions of Directive

¹⁰⁴ EU Council (2008) Final Draft Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation; See; <http://www.europarl.europa.eu/oeil/OpenDetailFiche.do?ficheld=1544&language=en> Paragraph 5, Article 2

¹⁰⁵ For information, Title III of the Charter of Fundamental rights contains the principle of non discrimination which is worded as follows, ‘any discrimination based on any ground such as sex race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be protected’. See; <http://curia.europa.eu/juris/cgi-bin/form.pl?lang=EN&Submit=rechercher&numaff=C-236/09> Paragraph 8.

¹⁰⁶ the mechanism by which individuals and States can take legal remedy

¹⁰⁷ EU Commission (2010) Disability Rights: EU and the Ratification of the UN Convention on the Rights of Persons with Disabilities. See; <http://europa.eu/rapid/pressReleasesAction.do?reference=MEMO/10/198&format=HTML&aged=0&language=EN&guiLanguage=en>

2004/113/EC on implementing the principle of equal treatment between men and women in the access to and supply of goods and services.¹⁰⁸

The European Court of Justice (ECJ) concluded that Article 5(2) of the Directive 2004/113 that allowed Member States to permit sex-specific differences in insurance premiums and benefits subject to the conditions stated in that article which permitted differences in insurance contracts, which are directly linked to the sex of the insured person, was invalid. Therefore taking the gender of the insured individual into account as a risk factor in insurance contracts constitutes discrimination".^{109 / 110}

In relation to insurance for volunteers, the DSD has proposed 'to work across government, the volunteering infrastructure and the insurance industry to limit the potential for insurance to be a barrier to volunteering'¹¹¹; however policy is awaited on the matter (see DSD comment at 5.1.4.1 above).

5.1.4.3. Equality Legislation

While legal comment is outside the remit of this study, the general nature of this article does require a brief comment on the current legislative situation within Northern Ireland. The introduction of the Equality Act 2010 in Great Britain has resulted in inequalities in protection for disabled people living in Northern Ireland compared to the rest of the UK and will inevitably lead to a potentially different application of the UNCRPD through local legislative and policy changes. This is an untenable position and the positive equalization of protection should be addressed as a matter of urgency.

The Equality Act 2010¹¹² will greatly impact on disability law and the barriers faced by disabled people in relation to their interaction with such areas as the state, housing and employment.

For example the Equality Act introduces;

- a single objective 'justification' test which replaces the different tests previously in use;
- new ways to claim for disability discrimination which remove the effect of the House of Lords decision in **LB Lewisham v Malcolm** (see below) which severely restricted the right to claim for less favourable treatment;

¹⁰⁸ See; <http://www.gelijkekansen.be/bijlagen/Internationaal/Bij%20EU/Dir%202004.113.EC.pdf>

¹⁰⁹ See; <http://www.bbc.co.uk/news/business-12606610>

¹¹⁰ Case C-236/09 (2010) See; <http://curia.europa.eu/jurisp/cgi-bin/form.pl?lang=EN&Submit=rechercher&numaff=C-236/09>

¹¹¹ DSD July (2009), 'Join In, Get Involved: Build a Better Future – A Consultation Paper on a Volunteering Strategy for Northern Ireland'. Proposal 18 - p24, DSD July 2009

¹¹² For a full explanation of the Equality Act see; <http://homeoffice.gov.uk/equalities/>

- there are new restrictions on employers asking about health and disability before deciding whether to offer employment;
- and for some types of discrimination, the new concept of 'perceived disability' should make it harder to escape liability by arguing an impairment had no substantial long-term effect.¹¹³

The case of **LB Lewisham v Malcolm** (a housing case) is significant in that the House of Lords decided that;

- 'in DDA premises claims, a disabled person must compare their treatment with someone who is in the same or very similar circumstances to show that they have been treated less favorably for reasons relating to disability. For example, in Mr. Malcolm's case, he would have to show that a non-disabled tenant or a tenant with a different disability who had sublet without permission was treated better and had not been, or would not be, evicted
- a premises provider must know about the disabled person's impairment - and possibly the effects of it - to discriminate for reasons relating to disability.

The House of Lords decision had the effect of making it more difficult for a disabled person to prove disability-related discrimination. The judgment means that for some types of disability discrimination cases the correct comparator for a disability-related discrimination claim is now the same as for a direct discrimination claim'.¹¹⁴ The Equality Act directly addressed this issue and redresses the balance in GB however it is not applicable in Northern Ireland.

An example of the impact of the current difference between Northern Ireland and GB, which is relevant to the progressive realisation of rights within Article 19 of the Convention, was highlighted by the ECNI.¹¹⁵ Under the Equality Act 2010 in GB, landlords and managers are required to make disability-related adjustments to the physical features of the common parts of let residential premises, where it is reasonable to do so and when requested by a disabled tenant or occupier, this is not the position under the Disability Discrimination Act 1995 in Northern Ireland.

¹¹³ For commentary on the Equality Act see for example <http://www.stammeringlaw.org.uk/changes/sea.htm>

¹¹⁴ For a full discussion of the Malcolm Case see; <http://www.equalityhumanrights.com/legal-and-policy/legal-updates/recent-developments-in-disability-discrimination-cases/the-malcolm-case/>

¹¹⁵ See http://www.equalityni.org/archive/pdf/Priorities_for_legislative_reform0602091.pdf

5.1.5. Results from the questionnaire and focus groups

Results from the questionnaire found that respondents indicated agreement that equality in employment was a gap between policy and the requirements of the UNCRPD2 with 26 out of 28 respondents strongly agreeing or agreeing. This was the second highest ranked perceived gap after Awareness Raising. The comments expressed in the questionnaire included:

“Less chance of employment - live on benefits - no way out of the poverty trap! Nowadays you are scum being on benefit (media) Being on benefit and no chance of employment where does that place disabled people?”.¹¹⁷

“There is a greater equality within education, but this needs to be matched in all government programmes and the benefit system needs looked at to reflect the standard of education disabled people are obtaining as the benefit trap can stop disabled people in certain circumstances going into employment”.¹¹⁸

5.2. Article 6: Women

Article 6 - Women with Disabilities

- 1 States Parties recognise that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
- 2 States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

Article 6 recognises that multiple forms of discrimination are experienced by women with disabilities and it imposes obligations on State Parties to take measures to ensure the ‘full and equal enjoyment’ by women with disabilities of ‘all human rights and fundamental freedoms’. It is significant that this article does not refer to the rights contained in UNCRPD alone, but to ‘all human rights and fundamental freedoms’. This means that State Parties

¹¹⁷ Comment from a IMNI Conference questionnaire respondent 1/12/2010

¹¹⁸ Ibid

must take measures to ensure the realisation of the rights of women with disabilities as contained in other instruments. Article 6(1) can be argued to require that any measures taken to protect or promote the human rights and fundamental freedoms of women explicitly include measures to specifically protect the rights of women with disabilities.

5.2.1. Consideration of other UN human rights treaties

The Committee on the Convention on the Elimination of Discrimination against Women (CEDAW), in its brief General Recommendation on women with disabilities, has recommended that States Parties provide information on disabled women in their periodic reports, and on measures taken to deal with their particular situation, **including special measures** to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life.¹¹⁹ This confirms the interpretation of Article 6 of UNCRPD as requiring special measures. The CERD Committee has identified a core obligation of States Parties to improve the de facto position of women through concrete and effective policies and programmes.

As such, the term 'measures' in this context has been interpreted by the Committee to encompass a wide variety of measures including policies and practices, such as outreach or support programmes; allocation and/or reallocation of resources; preferential treatment; targeted recruitment, hiring and promotion; numerical goals connected with time frames; and quota systems.

5.2.2. Comments from the Committee on the Rights of Persons with Disabilities

In the Guidelines on treaty-specific document to be submitted by States parties under Article 35, paragraph 1, of the UNCRPD, the Committee on the Rights of Persons with Disabilities has not provided guidance as to what exactly it expects States Parties to report with respect to Article 6.

5.2.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from Reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other State Parties. These Reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They

¹¹⁹ Committee on the Elimination of Discrimination Against Women (1991) General Recommendation No.18, 'Disabled Women'.

should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

In some of the State Reports which have been submitted, there is a lack of specific reference to women with disabilities and general information has been provided instead on measures taken to ensure women's rights. This leaves it unclear as to state views on their obligations under the Convention.

In its State Report, **Australia** makes clear that it is actively working to attempt to address past failings concerning women with disabilities and domestic violence. The strategy surrounding this is set out in the 'National Plan to Reduce Violence Against Women and their Children, the National Framework for Protecting Australia's Children' and the 'National Homelessness Strategy'. Furthermore, a number of individual women's organisations and six National Women's Alliances are provided with governmental funding to facilitate consultation with women with disabilities on issues that affect them. The information that is gathered through these consultations is then used to provide informed and representative advice to government on policy development and implementation relevant to the diverse views and circumstances of women.¹²⁰ Australia is thus clearly of the view that policies and programmes to address domestic violence against women with disabilities are a requirement of Article 6.

Austria takes into consideration gender mainstreaming and gender budgeting as part of its Employment Campaign 'Sheltered Work and the Provision of Occupational Qualifications'. A 'Health Forum for Girls and Women with Disabilities' was established in Austria and through this a number of brochures have been published to raise awareness. Austria clearly considers that measures specifically targeted at addressing employment and health rights for women with disabilities are the kinds of policies and programmes required by Article 6.

In **Spain** in December 2006 the Government adopted a First Plan of Action for Women with Disabilities which establishes a strategy for correcting the inequalities between men and women with disabilities. The Third Plan of Action which is aimed at all persons with disabilities incorporates the principles and measures of the earlier plan with the aim of addressing disability along gender-analysis lines. The Gender Unit in the Centre for the Rehabilitation of Physically Disabled Persons also proposed uniform standards for the use of non-sexist language in dealings with women with disabilities.¹²¹ These are clear examples which demonstrate that Spain understands that a range of policy and programme measures are required by Article 6.

¹²⁰ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 192-96.

¹²¹ CRPD/C/ESP/1, 'Report to the Committee on the Rights of Persons with Disabilities: Spain' (3 May 2010), at para 17-20.

5.2.4. Key policies and programmes in Northern Ireland relevant to Article 6

In general terms in Northern Ireland the rights of disabled women in society are safeguarded by equality legislation. However some areas of concern have been identified:

5.2.4.1. Maternity and sexual health services

The draft DHSSPS Equality plan 2011 concluded that marginalised women (with disabilities, traveller women and Black and Minority Ethnic (BME) women, younger women, rural women etc) have difficulty in accessing maternity services.¹²² A review of maternity provisions was begun by the DHSSPS (2010), however there is little evidence from examination of the project board minutes that the particular needs of disabled people as identified in the DHSSPS 2004 report, (such as difficulties in accessing key services such as reproductive health care and screening¹²³) are being incorporated into the study.

The draft DHSSPS Equality Plan also commented that people with disabilities are often considered to be asexual in relation to sexual health services,¹²⁴ a finding which repeats an ECNI conclusion in 2003.¹²⁵ This raises questions as to the adequacy of training for health staff with respect to women with disabilities and their healthcare needs.

A 2006 study of 260 health service managers and staff across four HSSBs in Northern Ireland on the sexual health and well being of people with learning disabilities¹²⁶ reported that 40% had some form of sexuality training mainly a one day (n=59) or two-day course (n=24). 63% knew the service policy on sexuality and 44% knew the service guidelines on sexuality. The study reported that the majority of front line staff in the study are in agreement that they must document or report instances of sexual enquiry or behaviour. The researchers commented that this suggests that staff are required to fulfil supervisory and reporting functions with respect to sexuality with limited scope for flexibility and respecting a client's privacy. The study further reported that staff feel under pressure from managers and parents to

¹²² Department of Health, Social Services and Public Safety (2011), 'Draft Equality Plan' v1 January 2011

¹²³ DHSSPS (2004) Equality and Inequalities in Health and Social Care: A Statistical Overview Report, 'Inequalities and unfair access issues'

¹²⁴ Department of Health, Social Services and Public Safety (2011), 'Draft Equality Plan' v1 January 2011

¹²⁵ ECNI (2003) 'Disabled Women in Northern Ireland: Situation, Experiences and Identity'

¹²⁶ Simpson, A. Lafferty, A. and McConkey R. (2006) 'Out of the Shadows: Our voices aren't going into the dark anymore: A report of the sexual health and wellbeing of people with learning disabilities in Northern Ireland', FPA Newnorth Print, Bedfordshire.

supervise and limit the sexual expressions of people with learning disabilities and they understood that this included a lack of privacy and disrespect for the person with a learning disability but feel powerless to do anything about it. The researchers concluded that greater dialogue between people with learning disabilities, staff, managers and carers is required so that misperceptions can be corrected and a culture of co-operation developed.

Concerns about staff attitudes were reflected by a female disabled representative participant in a focus group held for this study who commented;

“they assume that we can’t think or speak for ourselves, work, have children, need contraception, or smear tests... we can’t have a family, we have a disability, I am not a non person, they treat us as non persons.”¹²⁷

The Sexual Health Promotion Strategy and Action Plan 2008-2013 notes¹²⁸ that little is known about the sexual health of persons with a disability. It goes on to relate a list of areas where the service expected falls short for disabled people: for example in relation to physical access and access to sexual health information and advice particularly for those with a sensory impairment or learning disability e.g. provision of information in accessible formats such as audio tape, use of plain English and pictures and provision of sign language interpreters. The resultant Action Plan lists a series of measures with ongoing, short or medium term goals. However, with the exception of a new HSC strategy pending in April 2011 to end in 2014¹²⁹ (budgets permitting), it is unknown if any of the issues identified in the draft equality plan have been addressed.¹³⁰

One of the causes of this situation may be a lack of available data in relation to disabled people. The DHSSPS Draft Equality Plan 2011 commented that ‘generally the HSC data systems do not record all the s75 category information and this means that a lot of the findings are anecdotal and some were based on findings from outside Northern Ireland or from reports produced by representative/stakeholder organisations. In addition, in some cases the sources were fairly dated and the material may no longer be valid’.¹³¹

¹²⁷ Comment from a participant with disabilities in the Representative Scoping Focus Group, 14/1/2011

¹²⁸ See Appendix 1 <http://www.dhsspsni.gov.uk/sexualhealthstrat.pdf>

¹²⁹ Strategy to tackle the issue of people with a sensory impairment such as deafness or blindness accessing information about HSC services

¹³⁰ Department of Health, Social Services and Public Safety (2011), ‘Draft Equality Plan’ v1 January 2011

¹³¹ Department of Health, Social Services and Public Safety (2011), ‘Draft Equality Plan’ v1 Page 8, January 2011

Some examples of good practice have been noted for example the Family Planning (FPA)¹³² website which is part funded by the Health Protection Agency offers a range of information to persons with a learning disability. However there is little information in relation to other disabilities and the helpline does not include a text phone number.

An examination of the policies involved lead to the conclusion that the main difficulties in this area are awareness training, monitoring and data collection and accessibility issues. In the context of Northern Ireland, Article 6 must thus be examined alongside Articles 8, 9, 21 and 31.

5.2.4.2. Results from the Questionnaire and focus groups

Females comprised 65.9% (n=27) of the respondents to the questionnaire, and more female (n=11) than male (n=4) respondents were disabled. However the results from the questionnaire indicated that there were no gender specific themes.

The focus groups, which were more balanced with respect to gender compared to the questionnaire respondents also did not find much evidence of specific gender concerns.

5.3. Article 7: Children with disabilities

Article 7 - Children with disabilities

- 1 States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
- 2 In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
- 3 States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right.

¹³² See <http://www.fpa.org.uk/>

Article 7(1) places a strong obligation on State Parties to take ‘all necessary measures’ to make sure that children with disabilities fully enjoy the same human rights and fundamental freedoms on an equal basis with other children. This general obligation requires that all policies and programmes for children explicitly consider children with disabilities and ensure that their human rights are as effectively realised on an equal basis as those of children without disabilities.

Article 7(2) reiterates the general obligation to act in the best interests of children and any policies or programmes which relate specifically to children with disabilities must also enshrine this fundamental principle. The reiteration of this principle in the UNCRPD with respect to children with disabilities is to ensure that it is given due weight in decisions affecting them.

Article 7(3) reiterates the requirement on State Parties to ensure that children with disabilities, just as other children, are able to express their views freely on all matters affecting them and that their views be given due weight. However, it in addition requires that they ‘be provided with disability and age-appropriate assistance to realise that right’. This is a specific obligation in the UNCRPD which does not feature elsewhere in international human rights law and it has clear implications for policies and programmes which affect children with disabilities. First, it is not an obligation to make reasonable adjustments as part of an ‘access’ duty. The assistance provided is to enable the realisation of a particular right (‘to express their views’), and thus there must be explicit policies and programmes for facilitating the right to the expression of the views of disabled children in any situation where there are ‘matters affecting them’. Further, there must be a programme or programmes of ‘assistance’ in place to ensure the realisation of this right. Article 7(3) thus obliges State Parties to implement programmes of assistance based on clear policies ensuring the right of disabled children to express their views across all areas where ‘matters affect them’. Some non-exhaustive examples include: within health and social care, including treatment decisions; within criminal and civil justice; and within education.

5.3.1. Consideration of other UN human rights treaties

Article 3 of the Convention on the Rights of the Child states that the best interests of the child are a primary consideration in all actions concerning children. The principle of best interests therein applies to all actions concerning children including in the development of policies and programmes, and requires active measures to protect their rights and promote their survival, growth, and well-being, as well as measures to support and assist parents and others who have day-to-day responsibility for realising children’s rights. All decision-making concerning a child’s care, health, education, etc. must take account of the best interests principle, including decisions by parents, professionals and others responsible for

children.¹³³ The Committee on the Rights of the Child has also urged States Parties to develop rights-based, co-ordinated, multisectoral strategies in order to ensure that children's best interests are always the starting point for service planning and provision.¹³⁴

The right of the child to express their views in all matters affecting them, and for those views to be given due weight is set out in Article 12 of the Convention on the Rights of the Child. This right reinforces the role of the (disabled) child as an active participant in the promotion, protection and monitoring of their rights. The Committee on the Rights of the Child has asserted that the right to express views and feelings should be anchored in the child's daily life at home (including, when applicable, the extended family) and in his or her community; within the full range of early childhood health, care and education facilities, as well as in legal proceedings; and in the development of policies, programmes and services, including through research and consultations.¹³⁵ Specifically, children with disabilities should be equipped with, and enabled to use, any mode of communication necessary to facilitate the expression of their views.¹³⁶

As an example, the Committee on the Rights of the Child recommends that States Parties introduce measures enabling children to contribute their views and experiences to the planning and programming of services for their health and development. Their views should be sought on all aspects of health provision, including what services are needed, how and where they are best provided, discriminatory barriers to accessing services, quality and attitudes of health professionals, and how to promote children's capacities to take increasing levels of responsibility for their own health and development.¹³⁷

5.3.2. Comments from the Committee on the Rights of Persons with Disabilities

In the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities, the Committee on the Rights of Persons with Disabilities has not provided guidance as to what exactly it expects States Parties to report with respect to Article 7.

¹³³ Committee on the Rights of the Child (2007) General Comment 7, 'Implementing Child Rights in Early Childhood', at Para 13.

¹³⁴ Committee on the Rights of the Child (2007) at Para 22.

¹³⁵ Committee on the Rights of the Child (2007) at Para 14.

¹³⁶ Committee on the Rights of the Child (2009) General Comment 12 'The right of children to be heard', Para 21.

¹³⁷ Committee on the Rights of the Child (2009) Para 104.

In its Concluding Observations, the Committee on the Rights of the Child has indicated ways in which the UK can improve the situation of children with disabilities including:

- developing early identification programmes;
- providing training for professional staff working with children with disabilities;
- developing a comprehensive national strategy for the inclusion of children with disability in society; and
- undertaking awareness-raising campaigns on the rights and special needs of children with disabilities, encouraging their inclusion in society and to prevent discrimination and institutionalisation.¹³⁸

These requirements as to policies and programmes can be taken as the view of the Committee on the Rights of the Child as to what Article 7 (1) requires of the UK at the current juncture.

5.3.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from Reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other State Parties. These Reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

In its Report on Hong Kong with respect to Article 7, **China** refers to the setting up of Parents/Relatives Resource Centres and pre-school rehabilitation centres to provide parents with parent education activities and support. Thus China clearly considers Article 7 to require policies and programmes for parents of disabled children as well as the children themselves. The Department of Health provides additional support through co-ordinating a series of promotional activities, including a public education programme, radio interviews and publishing articles in local newspapers to enhance awareness of childhood developmental disabilities. This makes it clear that China considers the obligations of Article 7 to directly relate to other articles such as Article 8 on awareness-raising.

In its shadow report on **Spain**, CERMI calls for specific measures to be included in all care policies for minors to ensure that actions deployed reach

¹³⁸ CRC/C/GBR/CO/4, 'Committee on the Rights of the Child Concluding Observations: United Kingdom of Great Britain and Northern Ireland' (20 October 2008).

children with disabilities effectively and on an equal basis.¹³⁹ It is clear that the designated body under Article 33 (2) for Spain sees the existence of specific policy measures aimed at children with disabilities as an obligation under Article 7.

In its shadow report on Tunisia, the International Disability Alliance (IDA) states that special provision on the participation of children with disabilities and their right to express their views should be provided for within policies and programmes reflecting Article 7 of the UNCRPD.¹⁴⁰

5.3.4. Key policies and programmes in Northern Ireland relevant to Article 7

In Northern Ireland there are a number of bodies who ensure that the views of children are heard by Government. Some of these are fully State funded or are partially State funded. The main bodies include: Cruse Youth Advisory Group; Young NCB NI; NICCY Youth Panel; SELB and WELB Youth Councils; Young Voices project; the NIYF and Disabled Children and Young Persons Participation Project. Only the Disabled Children and Young Persons Participation Project¹⁴¹ works solely with disabled children, although the majority listed above do have some disability representation within their frameworks. A 'Network of Networks' is currently being developed to strengthen the direct voice of children and young people in all relevant aspects of government provision. The OFMdFM Children and Young Persons Conference, Be Seen, Be Heard¹⁴² in its summary report concluded that a key area for young people was participation and that government needs to show it is really listening.

NICCY has statutory duties in relation to participation and the Participation Network. The Participation Network is funded by the OFMdFM to enable the public sector to engage effectively with children and young people in the development and review of policy and services that impact on their lives. NICCY duties are set out in The Commissioner for Children and Young People (Northern Ireland) Order 2003, in that they are required to promote the participation of children and young people by listening to them and working with them to challenge and change the world they live in. They promote the awareness of and importance of the rights of children and young people to children and young people, their parents and those who represent them. Amongst other parts of this legislation, Articles 2 (2b), (5), Article 6(1) and Article 8(2), (5), also confer a requirement to ensure communication and participation involving children, young people, parents, guardians,

¹⁴¹ <http://www.engage.hscni.net/bestpractice/projects/childrensproject.html>

¹⁴² Be Seen, Be Heard: Children and Young People's Strategy Action Plan And The UNCRC Concluding Observations Youth Conference, OFMdFM, 21st November 2009

stakeholders and opinion formers.¹⁴³ NICCY regularly raise concerns that the duty placed on government and statutory authorities to consult with children and young people, through Section 75 and Article 12 of the UN Convention on the Rights of the Child is not adequately met; for example, in their consultation response on the Play and Leisure Implementation Plan¹⁴⁴ On the same topic, in a recent paper on how Councils deliver play and leisure,¹⁴⁵ it was noted that local Councils did not all routinely consult and involve children, including children with disabilities and at times, may have been consulting parents, carers and representative groups rather than engaging directly with disabled children. NICCY comment that they are aware of examples of good practice, such as Sixth Sense, but are concerned that these must be part of a more comprehensive strategy for inclusion.

The Participation Network recognises the particular requirements of disabled children and recommends that during consultations Government departments will work towards ensuring that materials are available in formats that are accessible to children and young people with sensory and learning disabilities.¹⁴⁶ The Network also promotes the use of partnership with specialist bodies which is especially important with regard to disabled children. To 2010, 81 Public Authorities have already accessed their training, consultancy, advice and technical support services. Enquiries are being made as to how many consultations enabled the participation of disabled children in the process.

Research has to date not found any evaluation of these services especially with regard to disabled children. A Big Lottery funded seminar, 'Working it Out: Participative Structures Seminar Report'¹⁴⁷ significantly did not discuss any particular difficulty or concerns about the participation of disabled children in the participation consultation process. Whether this reflects the true situation or whether the problem is unrecognised is unknown, however evidence from the focus groups and questionnaire suggests that there are concerns about a, "lack of direct engagement with children and young people with disabilities and their parents/carers".¹⁴⁸

¹⁴³ <http://www.niccy.org/Participation>

¹⁴⁴ <http://www.niccy.net/article.aspx?menuId=9755>

¹⁴⁵ Quoted in e-mail correspondence from NICCY 10th February 2011

¹⁴⁶ Participation Network (2010). Ask First: Northern Ireland Standards for Children and Young People's Participation in Public Decision Making

¹⁴⁷ http://www.niyf.org/cmsfiles/Publications/working_it_out.participative_structures_seminar_report.pdf

¹⁴⁸ Comment from questionnaire respondent and an IMNI Conference focus group identified policy gap 1/12/2010

5.3.5. Results from the questionnaire and focus groups

Views were sought from representative groups through the questionnaire and focus groups. While few comments were received exclusively about disabled children, two areas of specific concern were identified and these were the participation of disabled children and carers (discussed above) and education which is discussed further within the framework of Article 24.

This would suggest that targeted research is required to examine the views of disabled children with sufficient time and resources allocated to overcome any specific communication and access issues which may be encountered.

5.4. Article 8: Awareness raising

Article 8 - Awareness raising

- 1 States Parties undertake to adopt immediate, effective and appropriate measures:
 - (a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
 - (b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
 - (c) To promote awareness of the capabilities and contributions of persons with disabilities.
- 2 Measures to this end include:
 - (a) Initiating and maintaining effective public awareness campaigns designed;
 - (i) To nurture receptiveness to the rights of persons with disabilities;
 - (ii) To promote positive perceptions and greater social awareness towards persons with disabilities;
 - (iii) To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;

- (b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
- (c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
- (d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

Article 8 imposes a general obligation on State Parties to adopt awareness-raising measures. The aims of these awareness-raising measures are specified in Article 8(1) and Article 8(2) imposes obligations with respect to the means to be pursued by State Parties under this article.

Article 8/1 requires that measures be adopted to:

- Raise awareness regarding people with disabilities;
- Foster respect for the rights and dignity of persons with disabilities;
- Combat stereotypes, prejudices and harmful practices in all areas of life, including those based on sex and age;
- Promote awareness of the capabilities and contributions of persons with disabilities.

In addition, the Convention is explicit that these measures must be:

- effective;
- immediate; and
- appropriate

The requirement for 'effectiveness' means in practice that there must be evaluation of the impact of any measures taken and that these measures be adjusted in the light of such evaluation of their effectiveness. General programmes and policies which are not of confirmed impact in raising awareness would not meet the obligations of this article.

The requirement for 'immediacy' means that any State Party which ratifies the Convention must undertake such awareness-raising without delay. It underlines that the obligation of Article 8 is not one which is progressively realisable but has 'immediate' effect. This is clearly because the issues it aims to address in terms of attitudes towards people with disabilities, combating stereotypes, and promoting awareness of the capacities and contributions of people with disabilities are seen as being core means of achieving the object and purpose of the Convention.

Article 8(2) fleshes out in greater detail through examples the range of measures which State Parties are obliged to implement. It requires four main areas of work, but use of these for the awareness-raising purposes of Article 8(1) is not exhaustive of the obligation contained in Article 8(1). The areas within which awareness-raising work is required are:

- (a) Public campaigns;
- (b) Within all levels of the education system;
- (c) In all organs of the media;
- (d) Awareness-training programmes.

Further detail is provided in Article 8(2) (a) on what must be involved in public campaigns for awareness-raising. These details further elaborate on the aims contained in Article 8(1). Public awareness campaigns must be designed to:

- nurture receptiveness to the rights of persons with disabilities;
- promote positive perceptions and greater social awareness towards people with disabilities; and
- promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market.

The obligations which Article 8 imposes on State Parties with respect to policies and programmes are extensive, immediate and ongoing. This is due to the core nature of this article with respect to the promotion and protection of all of the rights contained in the substantive articles of the Convention.

5.4.1. Consideration of other UN human rights treaties

The Committee on the Rights of the Child, in the context of children with disabilities, has called upon States Parties to conduct awareness-raising and educational campaigns targeting the public at large and specific groups of professionals with a view to preventing and eliminating de facto discrimination against children with disabilities.

5.4.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 8 in the **Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities**, the Committee on the Rights of Persons with Disabilities requires that the State Report should contain information on the measures taken to raise awareness of persons with disabilities, to foster respect for their rights and dignity, their capabilities and contributions, and to combat stereotypes, and prejudices against them.

In particular, States Parties should report on:

- Public-awareness campaigns directed to general society, within the education system and actions undertaken through mainstream media;
- Actions undertaken to raise awareness and inform persons with disabilities and other parts of society on the Convention and the rights it includes.

5.4.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from Reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other State Parties. These Reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect.

They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

Australia describes in its Report that it conducted a 'National Human Rights Consultation' with the purpose of seeking the views of the Australian community on how best to protect and promote human rights in Australia. Under this a new Human Rights Framework was established which has undertaken a comprehensive suite of education initiatives. Annual National Disability Awards are held, events are run in celebration of International Day of Persons with a Disability, localised Offices for Disability have been set up, easily accessible copies of the UNCRPD have been distributed, and education and training is conducted on anti-discrimination legislation.¹⁴⁹

Austria's measures concerning Article 8 of the UNCRPD have included: peer counselling projects; a media cooperation project; a television advertising campaign; a film festival which included films on the theme of disabilities; gender and diversity seminars; distribution of easily accessible copies of the UNCRPD; conferences and support for awareness-raising campaigns run by civil society organisations. In addition, a number of projects have been run which include persons with disabilities including theatre productions, dance projects, painting and photo workshops, exhibitions, socio-cultural festivals and international integrative street theatre festivals.¹⁵⁰

China reported to the Committee that Hong Kong has established a range of administrative measures to raise public awareness. Focus has been put

¹⁴⁹ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 37-43.

¹⁵⁰ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 13-14.

on territory-wide publicity programmes, cross-sectoral collaboration in promotion of the UNCPRD, instilling an inclusive culture for the younger generation, raising awareness among civil servants and public education on mental health. More specifically, awareness-raising has occurred through educational workshops, promotional campaigns, competitions, TV docudrama series, radio programmes, exhibitions, summer programmes for children, establishing self-help organisations, introducing principles and good practice and ensuring that disability training is carried out at job inductions.¹⁵¹ China further reports that Macao has initiated a number of awareness campaigns. They have included the publication and distribution of a booklet containing the text of the UNCPRD, promotional activities, life camps, events to celebrate International Rehabilitation Day, and competitions to help persons with disabilities integrate into the community and to increase awareness regarding persons with disabilities, their dignity rights and needs. Furthermore, the Social Welfare Bureau and Legal Affairs Bureau carry out civil education in primary and secondary schools using both the curriculum and extra-curricular activities.¹⁵²

Spain has introduced a 'National Accessibility Plan 2004-2010' which provides for awareness-raising and training in the fields of accessibility and design for all among the general public, and in particular among entrepreneurs, public officials and professional who influence the design and management of accessible environments and systems.¹⁵³ In addition, Spain has adopted a number of 'Plans of Action for Persons with Disabilities'. These aim to promote personal autonomy through recognition of disability as a component of human diversity, and the formulation and implementation of public policies in such a way that persons with disabilities receive the same benefits as other citizens, thus guaranteeing them the exercise and enjoyment of their civil, political and social rights in a society cohesive in its complexity. The report comments that co-ordination exists between the communities and social services in promoting awareness of disability at grassroots level through outreach activities and material. It further comments that co-ordination also exists between social, health and education services to promote awareness among health and education personnel, particularly for the purposes of early detection of disability. Training activities on disability are also being conducted.¹⁵⁴

¹⁵¹ CRPD/C/CHN/1/Add.1, 'Report to the Committee on the Rights of Persons with Disabilities: Hong Kong' (30 August 2010), at para 8.2-8.20.

¹⁵² CRPD/C/CHN/1/ADD.2, 'Report to the Committee on the Rights of Persons with Disabilities: Macao' (30 August 2010), at para 26-28.

¹⁵³ CRPD/C/ESP/1, 'Report to the Committee on the Rights of Persons with Disabilities: Spain' (3 May 2010), at para 32-34

¹⁵⁴ Ibid

Tunisia has revised school curriculums, including all textbooks, at all levels of primary and secondary education, and made human rights education compulsory across the board in higher education for all undergraduate and graduate degrees. Sensitisation and awareness campaigns on disability have been conducted through radio, television and print media.¹⁵⁵

5.4.4. Key policies and programmes in Northern Ireland relevant to Article 8

The Northern Ireland Human Rights Commission (NIHRC) is responsible for monitoring Human Rights and the Equality Commission for Northern Ireland (ECNI) is responsible for promoting equality and dealing with anti-discrimination laws in Northern Ireland.

The Northern Ireland Act 1998 (Part 7)¹⁵⁶ and Sections 14 - 20 of the Justice and Security (Northern Ireland) Act 2007¹⁵⁷ comment that the NIHRC “shall promote understanding and awareness of the importance of human rights in Northern Ireland”. The ECNI has duties under the disability legislation with respect to anti-discrimination and equality of opportunity in the area of disability, including duties under Section 75 of the Northern Ireland Act 1998 and duties under the Disability Discrimination Act (DDA)1995 as amended by the Disability Discrimination (Northern Ireland) Order 2006.

However as detailed above, Article 8 of the UNCRPD goes beyond these duties and imparts on the State general obligations in relation to the raising of awareness regarding people with disabilities; fostering respect for the rights and dignity of persons with disabilities and combating stereotypes, prejudices and harmful practices in all areas of life, including those based on sex and age. These duties must be effective, immediate, and appropriate.

Recent research into public attitudes towards disability by ComRes for Scope¹⁵⁸ (online survey of 2,050 GB adults and 533 disabled people, 2011) suggests that “disabled people feel that public attitudes towards them have got worse over the past year”. The poll also found that 58% of disabled people thought others did not believe they were disabled and half of disabled people feel others presume they are not working.

Richard Hawkes, Chief Executive of the disability charity Scope, responding to the findings and recent Government spending decisions stated that the eroding of support will have an impact on attitudes in that “disabled

¹⁵⁵ CRPD/C/TUN/1, ‘Report to the Committee on the Rights of Persons with Disabilities: Tunisia’ (14 July 2010), at paragraph 65-73.

¹⁵⁶ <http://www.legislation.gov.uk/ukxi/2010/976/schedule/14/paragraph/78/made?view=plain>.

¹⁵⁷ <http://www.legislation.gov.uk/ukpga/2007/6/contents>.

¹⁵⁸ <http://www.scope.org.uk/news/attitudes-towards-disabled-people-survey>.

people will be unable to play their part in society, in the workplace, in shops, restaurants, offices and community spaces. It is visibility and increased familiarity in everyday life that challenges negative perceptions and attitudes towards disabled people. Unless disabled people can contribute to society, attitudes will continue to deteriorate and they risk being further excluded from society.”¹⁵⁹

Nick Acheson (2005),¹⁶⁰ commenting on public attitudes towards disabled people in Northern Ireland, reported that evidence (from the NI Life and Times Survey 2003-2004,¹⁶¹ n=1800 adults interviewed) suggests that “public attitudes towards disabled people are coloured by a rather narrow conception of the nature of disability, a concern to maintain a degree of social distance, particularly in the case of people with mental health problems and reactions dominated by feelings of pity and sympathy. In most instances there was no significant difference in the attitudes of disabled and non-disabled people”. He further comments that “this was compounded by a general lack of awareness of the relatively poor social and economic circumstances of disabled people (although it was higher than for other groups apart from elderly people). This constellation of attitudes has long been identified by disabled commentators as an important source of oppression”.

Interestingly, disabled people and non disabled people were consistent in which circumstances they were more likely to judge people as ‘disabled’, with the highest priority given to people with mobility problems and progressive illness and the lowest to severe disfigurement and speech impairment. Acheson also noted the low proportion of respondents who considered a learning difficulty as a disability.

Acheson comments that “there is a fair way to go before public attitudes ‘catch up’ with public policy”, and that it will be disabled people who will force changes in attitudes but that the “lack of evidence of significant differences in the attitudes of non-disabled and disabled people offers a cautionary note as to how soon this might occur¹⁶²”.

The Northern Life and Times survey examined disability again in 2009¹⁶³ (n=1228 adults) although it examined social attitudes towards disability and it appears that none of the questions asked in 2003 were directly re-examined. No direct analysis of the results appears to have been published

¹⁵⁹ <http://www.scope.org.uk/news/matthew-parris-and-times>.

¹⁶⁰ Acheson N., (2005) Public Attitudes towards Disability in Northern Ireland, Research Update 35, March 2005.

¹⁶¹ www.ark.ac.uk/nilt

¹⁶² Acheson N., (2005) Public Attitudes towards Disability in Northern Ireland, Research Update 35, March 2005, Page 4.

¹⁶³ ARK. (2009) Northern Ireland Life and Times Survey. [computer file]. www.ark.ac.uk/nilt

although results are available on the Ark website. Unfortunately an analysis of the data is outside the remit of this study however some are some directly relevant questions to attitudes towards disability.

In response to the question, 'You have said that in general disabled people cannot always lead as full a life as non-disabled people. Why do you think this is?' 39% of people believed that it was solely due to their health problems and disability and was not due to attitudes, barriers and behaviours in society or a combination of these with disability or health problems (number of respondents unknown from the table).

Lastly in response to the Question, '**Overall, do you think attempts to give equal rights to disabled people have gone too far or not gone far enough?**' 45% of respondents believe that they have gone too far or are about right. 46% believe that they have not gone far enough (number of respondents unknown from the table).

There is some direct evidence in relation to the awareness of the UNCRPD from the Young Life and Times Survey 2010¹⁶⁴. This survey of 16 year olds (n=786), reported that 31.9% of young people had heard about the UN Convention on the Rights of People with Disabilities' compared to 39.6% who had heard about the UN Convention on the Rights of the Child' which has been in force longer. This is an encouraging finding. The survey also found that 8% of the respondents reported having a long standing illness or disability. This is higher than the percentage reported for 16-25 year olds living in private households (5%) by the Northern Ireland Research Agency 2007¹⁶⁵.

The ECNI and the NIHRC have been designated by the OFMdfM as the independent mechanism (IMNI) under Article 33(2) UNCRPD. IMNI explained its role in relation to awareness raising of the UNCRPD in the document "Independent Mechanism for Northern Ireland: Roles & Responsibilities within the Framework of Article 33" (known as the 'framework paper')¹⁶⁶.

The paper reports that, as an 'independent' element within the framework, the "Independent Mechanism for Northern Ireland shall not be considered as an organisation to decide upon legislation and policies, or to engage in other decision-making processes, for the State Party's implementation of the Convention, but to help facilitate implementation through its assessment of the State Party's actions and its actions to encourage full implementation of the Convention's provisions".

¹⁶⁴ <http://www.ark.ac.uk/ylt/2010/index.html>

¹⁶⁵ NISRA (2007) 'The Prevalence Of Disability And Activity Limitations Amongst Adults And Children Living In Private Households In Northern Ireland'..

¹⁶⁶ http://www.equalityni.org/archive/pdf/CRPD4_2aFrameworkPaper.pdf

The paper further states, “that in carrying out its independent functions, the Independent Mechanism for Northern Ireland is required to promote, protect and monitor the implementation of the Convention in Northern Ireland In regard to promotion of the Convention, the Independent Mechanism will take forward work to promote the State Party’s responsibility to implement the Convention. In promoting the State Party’s responsibility to implement the Convention, the Independent Mechanism may be required to promote the Convention itself alongside the responsibilities placed upon government. It is not the Independent Mechanism for Northern Ireland’s responsibility to promote the Convention on behalf of the State Party, or to publicise the State Party’s implementation of the Convention”¹⁶⁷.

The research team would agree with the comments of the IMNI in that the independent body should not perform the function reserved for the State especially such a critical requirement as that under Article 8.

It is recognised that the State in the form of the OFMdfM has begun the process of awareness raising through the establishment of the Promoting Social Inclusion (PSI) working group on Disability in 2004 which reported in 2009. However it is disappointing that the OFMdfM response to the recommendations of this report is still awaited although it is understood Departments met with the OFMDFM in February 2011 to review progress.

As a result of its work the PSI group recognised the central nature of awareness raising in promoting inclusion commenting that, ‘Our goal is to create a culture where positive attitudes are promoted towards disabled people, one in which their needs are mainstreamed into all aspects of life and where all services are delivered on a rights basis and in an appropriate and supportive way’.¹⁶⁸

This research has revealed a belief that the establishment of disability champions in local councils and in some government departments has increased confidence amongst disabled people that their requirements are being considered. This belief appears to be linked to the presence of a central point of contact and the desire for increased co-operation by Public Authorities.

“OFMdfM over arching responsibility, (should be a) top down strategy. Cross departments e.g. like Race champions – joined up working”.¹⁶⁹

¹⁶⁷ Ibid

¹⁶⁸ OFMdfM (2009). Report of the Promoting Social Inclusion Working Group on Disability, Page 13.

¹⁶⁹ Comment from a participant in the Representative Scoping Focus Group on the 10/1/11

“Political parties should have disability champions – separate from Equality Officers”.¹⁷⁰

However no evaluation study of the influence of disability champions has been identified. There is also some evidence that the situation may not have significantly improved for disabled people, for example as previously reported, in a 2011 paper on how Councils deliver play and leisure¹⁷¹ it was noted that they did not all routinely consult and involve children, including children with disabilities and at times may have been consulting parents, carers and representative groups rather than engaging directly with disabled children.

The importance of measuring the effectiveness of policies for disabled people is contained within Article 8 and was recognised by the PSI report and it is disappointing that such measures and the dissemination of these to disabled people is not recognised as a priority.

This research also notes that under Section 49 of the Disability Discrimination (NI) Order 2006, referred to as ‘the disability duties’, public authorities, when exercising their functions, must have due regard to the need to promote positive attitudes towards disabled people. The disability duties require public authorities to submit to the Equality Commission disability action plans showing how they propose to fulfil the disability duties in relation to their functions. These disability action plans must, as regards form and content, conform to the requirements of chapter 4 set out in the Commission guide to the disability duties¹⁷². Public Authorities are also required to produce an annual report on what progress they have made in implementing their disability action plans. Public Authorities must review their Disability Action Plans at the same time as their Equality Schemes and submit these reports to the Equality Commission.

This process has been commented on by the ECNI 2009 report¹⁷³ which noted that there was a lack of focus on monitoring and evaluation of disability action plans. None of the 21 public authorities assessed in the research¹⁷⁴ reported having systems in place to monitor and evaluate their disability action plan as a whole. Indeed, one public authority concluded that “our size militates against any formal measure”.¹⁷⁵ The report further

¹⁷⁰ Comment from a participant in the Thematic Focus Group on Participation in Political and Public Life on the 26/1/11

¹⁷¹ Quoted in e-mail correspondence from NICCY 10th February 2011.

¹⁷² ECNI (2007) A Guide for Public Authorities – Promoting positive attitudes towards disabled people and encouraging the participation of disabled people in public life.” ECNI: Belfast

¹⁷³ ECNI (2009) Effectiveness of the Disability Duties, Review report

¹⁷⁴ McIlWhan R, Rogers S. and Bridge S. (2009). Evaluating the Effectiveness of the Disability Discrimination (NI) Order 2006 Duties ECNI: Belfast, (Page 19).

¹⁷⁵ ECNI (2009) Effectiveness of the Disability Duties, Review report

commented that, 'the Commission (ECNI) has limited formal powers of enforcement regarding the disability duties -reporting non-compliance to the Northern Ireland Assembly and Judicial Review. It was the view of the researchers that the lack of formal enforcement powers, essentially only being able to name and shame public authorities in the report to the Assembly, has impacted on the ability to "effect meaningful action where a public authority has not taken steps to comply with its duties"'.¹⁷⁶

These duties may form part of the State's response to its fulfilment of its response to the requirements of Article 8 UNCRPD, however the scale, for example, in raising awareness throughout society and the scope of the article to include awareness at the family level is beyond that contained in the disability duties. The UNCRPD duties under Article 8 will require intervention in all functions of the State to ensure compliance with the Convention. Whether this is through in part the mechanism of the DDO is unknown, although changes to its guidance and policy will be required if this were to be the case.

In relation to OFMdfM, it is noted that in its current Disability Plan 2008-2011, the only referral to the UNCRPD is to set up the IMNI by December 2008 and to work with the two Commissions to raise awareness of the rights contained within the Convention. No additional UNCRPD specific policies or funding streams to fulfil the duties of the State have yet been announced; however the OFMdfM local jurisdiction report on the UNCRPD, if published, may outline future plans in this regard.

The Northern Ireland Executive has worked with disabled people and their organisations on promoting mental health and emotional well-being. This includes programmes and awareness campaigns to tackle the stigma attached to mental health conditions through the Bamford consultations and also through a limited series of workshop engagement events with disabled people and their organisations on the Convention. However the current level of awareness raising does not fulfil the requirements of Article 8 which will have policy implications for all departments of State and will include interventions to change society through engaging with the media, the education system, the business and trade union sectors, faith groups and political parties. The OFMdfM awareness strategy is awaited.

¹⁷⁶ McIlWhan R, Rogers S. and Bridge S. (2009). Evaluating the Effectiveness of the Disability Discrimination (NI) Order 2006 Duties ECNI: Belfast, (page 26).

5.4.5. Awareness raising in the media and education

5.4.5.1. Media

“Media needs to be involved, look at the success of the Drink driving campaign. Any campaign should examine the difficulties and use the correct language and people – a person with a disability. The campaign should involve disabled people in the planning and creation of the campaign”.¹⁷⁷

The media is a potent force in countering stigma and misinformation and a powerful ally in changing perceptions, eliminating discrimination, and raising public awareness, it will be one of the greatest aids to the state in creating the seismic change in society in attitudes towards disabled people. The Broadcasting media in particular has changed rapidly with a plethora of channels on offer via freeview, cable, satellite and most recently the internet through on demand TV, Youtube, and social media sites. In these circumstances the portrayal of disability is difficult to monitor and more difficult to influence due to the different attitudes towards disability in the programme country of origin and the different regulations which apply to some media sources.

TV Broadcasting in Northern Ireland was examined by the Northern Ireland Affairs Committee who reported in January 2010.¹⁷⁸ It is noted that broadcasting remains a matter reserved to Westminster and as such the influence of the OFMdfM may be limited.

The Northern Ireland Affairs Committee made a number of interesting conclusions on TV Broadcasting based on the extensive evidence that it had received. The committee observed that had ‘been struck by the absence of a strong or, often, any portrayal of the ordinary life of Northern Ireland to the rest of the UK. Coverage has concentrated largely on the Troubles and little else of life in Northern Ireland’.¹⁷⁹ Production levels were also low compared to the rest of the UK (the current output for the BBC National Network is about 1%).¹⁸⁰

The committee commented that, ‘one of the difficulties of devolution is that neither the Northern Ireland Assembly nor the Northern Ireland Office

¹⁷⁷ Ibid

¹⁷⁸ Report from the Northern Ireland Affairs Committee (2010) TV Broadcasting In Northern Ireland. <http://www.publications.parliament.uk/pa/cm200910/cmselect/cmniaf/237/23703.htm>

¹⁷⁹ Ibid, paragraph 2

¹⁸⁰ Report from the Northern Ireland Affairs Committee (2010) TV Broadcasting In Northern Ireland. <http://www.publications.parliament.uk/pa/cm200910/cmselect/cmniaf/237/23703.htm>

is responsible for broadcasting in the Province. Instead, that responsibility remains with the Department for Culture, Media and Sport, at Westminster' and commented that there appeared to be little engagement with Northern Ireland. 'The publication Digital Britain (White Paper) contains several illustrative maps of Great Britain. Of Northern Ireland, there is no sign'.¹⁸¹

In evidence to the committee it was commented that representation is often stereotypical. Mr Richard Hill, Chairman of Northern Ireland Screen, added: 'Sometimes to get a Northern Ireland accent on the network is hard work, never mind a programme on the network that might actually be about Northern Ireland [...] It is one thing to have our accents heard, it is another step to have, say, a returning drama series or a regular series in Northern Ireland as you might find in other parts of the UK'.¹⁸²

The Committee while commenting that broadcasting should remain a reserved matter commented that, 'Government seek to engage with broadcasters and producers so as more accurately to reflect life as it is in Northern Ireland in a way that is understandable throughout the rest of the UK. We recommend that the Government encourage the BBC and Channel 4 to use programmes made within the province for UK-wide broadcasting to address the lack of portrayal and to help ensure the people throughout the rest of the UK have a clearer perception of Northern Ireland - its people, its geography and wildlife, history and culture; and of its history and culture in times before the Troubles'. (Paragraph 30)

The committee also recommended that the Government should assess the non-news based needs of Northern Ireland, and also actively and urgently consider devolving to the Northern Ireland Assembly the administration of funding for local, non-news programming possibly to include drama, children's content and current affairs in Northern Ireland. (Paragraph 50).

With regards to the UNCRPD it remains the Westminster Government remit to influence the media through OFCOM and commissioning / funding in the portrayal of disability in the broadcasting media. The Northern Ireland Affairs Committee would argue for some devolution to Northern Ireland for non news programming and an opportunity may exist for local government influence with regard to Article 8 UNCRPD through this medium. Further opportunities are available for the OFMdfM, subject to funding, for campaigns such as the successful local anti drink campaign as reported above by the Focus Group participants.

Focus group participants stressed the importance of local discussion. It was considered the state's responsibility to have media campaigns and that

¹⁸¹ Ibid, paragraph 6-7

¹⁸² Ibid, paragraph 27

they should also use **“new media especially for younger people e.g. facebook, twitter, websites and have discussions on programmes such as Stephen Nolan or Spotlight”**¹⁸³.

With regard to current locally produced programmes, a brief examination by the research team would suggest that media portrayals of disabled people are confined to news items and current affairs and would tend to be about reaction to budgets reductions, changes to benefits, the misuse of benefits and good news / achievement reports. The researchers are unaware of any Northern Ireland based study on the matter.

Nationally, Ofcom reported on the ‘the representation and portrayal of people with disabilities on analogue terrestrial television’ in 2005.¹⁸⁴ It reported that:

- In 2004, 12% of sampled programmes (on BBC1, BBC2, ITV, Channel 4 and 5) included representations of people with disabilities. However, less than 1 person/character in 100 in the sampled programmes had a disability.
- Repeat appearances by the same person/character constitute around a quarter of all representations on television of people with disabilities.
- Both of these measures provide evidence of under representation on analogue terrestrial television of people with disabilities in 2004.
- Roles filled by people/actors with disabilities were more commonly those of children and retired people, both of which can be associated with vulnerability. This may reflect stereotyping in on-screen portrayals of people with disabilities.

“BBC and other channels on TV use pretty disabled actors, no speech difficulties or disfigurements”.¹⁸⁵

The National Disability Authority (NDA) of Ireland in 2008 published a report entitled, ‘Representation of people with disabilities in Irish broadcast media - a Review of Other Jurisdictions’ which concluded that in relation to the UK, the representation of people with disabilities in the United Kingdom’s broadcast media is very much a prevalent and evolving topic. Disability equality obligations, embedded in both disability and broadcasting legislation, have compelled the UK’s broadcasting sector (both public and private) to adopt a series of extensive measures aimed at advancing such representation both on and off air.

¹⁸³ Comment from a participant in the Thematic Focus Group on Awareness Raising. 19/1/2011

¹⁸⁴ <http://stakeholders.ofcom.org.uk/market-data-research/tv-research/portrayal/>

¹⁸⁵ Comment from a participant in the Thematic Focus Group on Awareness Raising. 19/1/2011

The report listed several measures taken by the broadcasting companies which included consultation exercises and on screen disability targets, most of which claimed to have been met. For example the BBC have made a commitment to:

- Three factual and leisure shows on BBC One and BBC Two to feature at least one disabled contributor per series (Beyond Boundaries, BBC Two - 11 disabled contributors; Ade Adepitan (previously from Xchange, BBC One and CBBC) now contributes to Sportsround, BBC One and Grandstand, and covered the new wheelchair doubles event at Wimbledon);
- Three key entertainment series on BBC One and BBC Two to feature a minimum of one disabled contestant in 50 (Weakest Link and Jet Set on BBC One, Mastermind on BBC Two).

The report concludes that in a comparative analysis of different countries:

“Cooperation and consultation by the media with people with disabilities and their representative organisations is important for a full understanding of their perspectives and the issues affecting them. Developing ongoing relationships with government agencies, representative groups, experts in related areas (legal, social, health, etc.) to provide best quality, appropriate and effective measures, information, skills, resources, etc., appears to be the most efficient way to address the issue of improving the representation of people with disabilities in broadcasting.....Targeting the education sector, particularly journalism courses in third level institutions, also appears to be a worthwhile step. The requirement to draw up diversity management or action plans seems to help to create and sustain awareness on the part of broadcasters and to create an environment for developing and monitoring progress” .¹⁸⁶

Despite examples of positive developments including the support given to a disabled TV children’s presenter Cerrie Burnell¹⁸⁷ and the BBC’s commitment to the inclusion of disabled people in mainstream programming such as ‘Beyond Boundaries’ and ‘I’m With Stupid’¹⁸⁸, some commentators have criticised the extent to which the media and the BBC in particular due to its public funding, have failed to deliver on their public service remit in relation to disability.¹⁸⁹ Negative portrayals of disability still remain far too common

¹⁸⁶ [http://www.nda.ie/cntmgmtnew.nsf/0/588299199D4C28C7802575F500296134/\\$File/media_rep_review_13.htm](http://www.nda.ie/cntmgmtnew.nsf/0/588299199D4C28C7802575F500296134/$File/media_rep_review_13.htm)

¹⁸⁷ <http://www.dailymail.co.uk/femail/article-1158343/Why-armed-BBC-presenter-Cerrie-Burnell-proud-debate-disability-provoked.html>

¹⁸⁸ http://www.bbc.co.uk/bbctrust/assets/files/pdf/regulatory_framework/diversity/disability.pdf

¹⁸⁹ Evidence of Dr Paul Darke to the Commons Select Committee on Culture, Media and Sport November 2006 reported at <http://www.parliament.the-stationery-office.co.uk/pa/cm200708/cmselect/cmcmds/36/36we05.htm>

and accepted in the media. For example, a Channel 4 executive commenting on a Frankie Boyle joke on disability said that he had personally approved the jokes and that Channel 4 had a duty to “test these boundaries”.¹⁹⁰

Scope has stated that “Changing attitudes is about visibility and increased familiarity in everyday life. It’s about first-hand experiences that challenge negative perceptions. But tackling language is part of that process. The way we think shapes the way we speak, but at the same time the way we speak has an impact on the way we think... Many people stopped using racist language as the way they thought about Jewish or African people changed – maybe as a result of working alongside them or other shared experience”¹⁹¹.

While acknowledging the positive movement in the media, these changes fall short of the State backed media action required to fulfil the positive change in attitudes and awareness required under Article 8.

5.4.5.2. Education

The importance of raising awareness in families was raised by focus group participants and it was considered that the best way to achieve this was through the child’s education. However participants reported that:

“Information on disability is not normally given although this differs between schools. There is policy. Someone needs to do a school pack”¹⁹².

The referral under Article 8, 2(iii)b that the State should foster at all levels of the education system including in all children from an early age, an attitude of respect for the rights of persons with disabilities, this has particular implications for Education. Enquires with the Department of Education have revealed that Local and Global Citizenship at Key Stage 3 (KS3) and Key Stage 4 (KS4) (the detail of the courses are available on the CCEA website) have inclusion and diversity, equality and social justice as core components throughout the courses and that pupils should explicitly consider the human rights of all. Specific reference is also given to groups mentioned in Section 75 and all teachers in post primary have resources to assist them in the course delivery. However, the guidance available, for example in KS3,¹⁹³ makes no reference specifically to either the UNCRPD or the specific duties under it, and which Section 75 group is examined is a matter for the teacher or school or Board. Further information has revealed that there has not been a thematic inspection on the teaching of disability awareness in schools or

¹⁹⁰ <http://www.mencap.org.uk/news.asp?id=21399>

¹⁹¹ <http://www.scope.org.uk/news/matthew-parris-and-times> (2011)

¹⁹² Comment from participant at the representative scoping focus group on the 10/1/2011

¹⁹³ http://www.nicurriculum.org.uk/docs/learning_for_life_and_work/training/LLW-Guidance.pdf

its effectiveness.¹⁹⁴ Resources are available for teachers on human rights and Section 75 groups but these do not seem to be disability specific¹⁹⁵. The research team understand that in the Spring of 2011 OFMdfM commissioned a presentation pack on Disability / UNCRPD for Schools.

It is also noted that in the Department of Education's draft Disability Action Plan for 2010 to 2013, no specific measure is included to address the requirements of Article 8 2(iii) b. However, it also comments that when completing the Equality and Human Rights screening form, policy makers will be asked to consider the human rights implications of policies - including the UNCRPD.¹⁹⁶

5.4.6. Results from the questionnaire and focus groups

Awareness raising was consistently the main gap area highlighted by disabled people and representatives in the focus groups and from the conference questionnaire and workshop¹⁹⁷. Results demonstrated the central position of awareness raising to disabled people and representatives from the voluntary and public sector in a successful implementation of the UNCRPD and an improvement in the lives of disabled people. There was also a clear message that disabled people and their representatives should be a central pillar in the creation of these campaigns.

A questionnaire respondent reported that there was a need to - **“raise awareness and improve understanding of disabilities and their impact among public representatives, professionals and administrators and improve the policies and services delivered”**. Participants commented that there was **“not enough awareness at all levels, not just in schools”**. Participants recommended ‘public campaigns, like the **“hard hitting ads for drink driving”**¹⁹⁸.

Lack of awareness was linked to access issues, **“Accessibility within the shop aisles. They think about ramps but not other things (awareness raising) Shop workers / everyone’s perception – raise awareness”**¹⁹⁹.

“Ignorance, assumptions, why are we not listened to?”²⁰⁰.

¹⁹⁴ Information from the Equality team DENI January 2011

¹⁹⁵ Correspondence with the SEELB January 2011

¹⁹⁶ http://www.doeni.gov.uk/disability_action_plan_-_1_april_2010_-_31_march_2011.pdf

¹⁹⁷ The full list of comments is contained in Appendices 2 & 3 of this report

¹⁹⁸ Comment from a participant in the Representative Focus Group on the 10/1/2011

¹⁹⁹ Comment from a participant in the Scoping Focus Group on the 10/1/2011

²⁰⁰ Comment from a participant in the Scoping Focus Group on the 15/12/2010

Respondents reported that **“parents of disabled children and disabled children are being excluded by being kept out of the social stream (clubs, parties etc) and that there should be more awareness of this”**²⁰¹.

In relation to religion, respondents commented that **“beliefs have an impact on how disability is perceived. It was a sin - the person or parent of a disabled child did something wrong so is punished with a disability”**²⁰². It was believed that this may also affected some migrant groups. Respondents considered that awareness raising through the church was a good way to change attitudes in certain communities.

“Awareness raising also applies to disabled people”²⁰³. **“Raise awareness with schools, statutory bodies, scouts, and youth clubs”**²⁰⁴. It was considered best practice to have **“disabled people giving the training as they had been through the experience”**²⁰⁵.

The importance of the family was stressed by participants and it was considered that this should be the **“first point of action”**²⁰⁶ for awareness.

Focus group participants believed that the Government should have one person with overall responsibility and there was general support for a Commissioner. Although if overall responsibility remains with the Disability Unit of the OFMdFM then greater awareness raising of its identity, function and responsibilities is recommended.

It was commented that there should be considered planning and co-ordination and not knee jerk reactions and quick fixes.

Participants reported that the current divided politics in Northern Ireland may result in a lack of political will to implement the UNCRPD.

Planning must be flexible and not written in stone. A participant giving an example of this reported that a disability plan for 2008-2011 on the NI Assembly website made no reference to the UNCRPD. When this was questioned by the participant it was commented that the UNCRPD had come into effect after the disability plan.²⁰⁷

²⁰¹ Comment from a participant in the first Thematic Focus Group (Awareness Raising) the 19/1/2011

²⁰² Ibid

²⁰³ Ibid

²⁰⁴ Ibid

²⁰⁵ Ibid

²⁰⁶ Ibid

²⁰⁷ Note: A public authority can change their disability action plan at any time as set out in the ECNI guide to the disability duties. An examination of a sample of Disability Action Plans at the time of writing (Spring 2011) revealed that very few public authorities had changed their Disability Action Plans to reflect the requirements of the UNCRPD or made reference to it.

Participants commented that awareness raising by government was needed in relation to the supply of information, not only amongst government employees, but also with disabled people. It was commented that signposts to information on the UNCRPD and disability should be available in places people frequent, including Doctor's surgeries, hairdressers, post offices and supermarkets.

5.4.7. Key area

From an examination of this article, desktop research, discussions with key stakeholders and the results from the conference questionnaire, workshop and focus groups, it became clear that Article 8 was a key area for the successful implication of the UNCRPD as it is the primary driver for change in attitudes towards people with disabilities. The implications of this and evidence from the focus groups will be discussed in later chapters.

5.5. Article 9: Accessibility

Article 9 - Accessibility

- 1 To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- (b) Information, communications and other services, including electronic services and emergency services.

- 2 States Parties shall also take appropriate measures to:
 - (a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
 - (b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
 - (c) Provide training for stakeholders on accessibility issues facing persons with disabilities;
 - (d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
 - (e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
 - (f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
 - (g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;
 - (h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Article 9 is clearly what might be termed a 'core' article of the Convention in that the obligations it imposes on States Parties have wide ranging significance for how effectively many of the rights contained in the UNCRPD are realised, or on the extent to which other obligations are met.

There is not currently agreement internationally on whether Article 9 only imposes obligations on States Parties or whether it creates a free-standing

right to access.²⁰⁸ There are other possibilities - one would be that it contains a right, but only when in conjunction with another right contained in the Convention (much as article 14 of the European Convention on Human Rights operates). Since policies and programmes may be required in fulfilment of a right or through being a requirement of an obligation, there is no need to conclusively determine whether there is a free-standing right in order to clarify at least many of the obligations imposed on States Parties by Article 9.

Article 9 imposes obligations on States Parties which have the purpose of enabling persons with disabilities 'to live independently and participate fully in all aspects of life'. It requires that States Parties take 'appropriate measures' to ensure access to persons with disabilities 'on an equal basis with others'. The measures are required to ensure access to:

- the physical environment;
- transportation;
- information and communications (including technologies and systems); and
- other facilities and services open to or provided to the public.

The requirement to ensure access explicitly applies to both urban and rural areas.

The definition of 'persons with disabilities' in Article 1 of the Convention is helpful in understanding the full meaning of Article 9 (1). It reads:

"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

Article 9 (1) requires that the measures taken by States Parties shall "include the identification and the elimination of obstacles and barriers to access". This clearly positions Article 9 as aiming at core processes of 'disablement' of individuals with impairments and its obligations thus acquire a particularly 'hard' character in the light of this intimate relation with the object and purpose of the Convention.

²⁰⁸ See the papers prepared for the "Day of Discussion on Article 9" which was held by the Committee on the Rights of Persons with Disabilities at its 4th Session on 7 October 2010. These submissions and some of the presentations are available at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGD7102010.aspx>

According to Article 9 (1) (a) the measures to identify and eliminate barriers must be applied to:

- buildings;
- roads;
- transportation; and
- other indoor and outdoor facilities.

The 'facilities' are further ostensibly defined as including:

- schools;
- housing;
- medical facilities; and
- workplaces.

According to Article 9 (1) (b) the measures to identify and eliminate barriers must be applied to:

- information services;
- communication services;
- 'other services', including 'electronic services' and 'emergency services'.

Article 9 (1) clearly imposes obligations on States Parties with respect to a wide range of policies and programmes which are only identifiable in detail through the context of a particular State. For instance, it is clear that the more complex and diverse the medical system of a State, the greater the range of policies and programmes that are likely to be required to ensure its accessibility to persons with disabilities.

Article 9 (2) (a) to (h) expands on the obligation of Article 9 (1) through a list of further 'appropriate measures'. Article 9 (2) (a) deals with standards and guidelines for the accessibility of facilities and services open or provided to the public. In connection with these standards and guidelines, States Parties have a tripartite obligation to:

- develop them;
- promulgate them; and
- monitor the implementation of them.

Article 9 (2) (b) requires States Parties to ensure that private entities who offer services or facilities which are open or provided to the public 'take into account' all aspects of accessibility.

Articles 9 (2) (c) to (e) place an obligation on States Parties to actually provide something as follows:

- Article 9 (2) (c) requires States Parties to provide training for stakeholders on accessibility issues.

- Article 9 (2) (d) requires States Parties to provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms.
- Article 9 (2) (e) requires States Parties to provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public.
- Articles 9 (2) (c) to (e) impose an obligation directly on State Parties and thus require State policies and programmes of sufficient depth and breadth to ensure that what the Convention requires is provided.

Articles 9 (2) (f) to (h) place an obligation on States Parties to actually **promote** something as follows:

- Article 9 (2) (f) requires States Parties to promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information.
- Article 9 (2) (g) requires States Parties to promote access for persons with disabilities to new information and communications technologies and systems, including the Internet.
- Article 9 (2) (h) requires States Parties to promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

The obligation to ‘promote’ is weaker than that to ‘provide’ in that it does not require the actual achievement of the outcome in order to meet the obligation. Nevertheless, policies must be as necessary and there must be programmes to ensure that ‘promotion’ does in fact take place.

5.5.1. Consideration of other UN human rights treaties

The Committee on the Rights of the Child, in the context of children with disabilities, has encouraged States Parties to set out appropriate policies and procedures to make public transportation safe, easily accessible to children with disabilities, and free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child. In addition, all new public buildings should comply with international specifications for access of persons with disabilities and existing public buildings, including schools, health facilities, governmental buildings, shopping areas, undergo necessary alterations that make them as accessible as possible.²⁰⁹

²⁰⁹ Committee on the Rights of the Child 43rd session (2006) General Comment 9 ‘The Rights of Children with Disabilities’ paras 39-40.

5.5.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 9 in the **Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities**, the Committee on the Rights of Persons with Disabilities requires that the report should cover:

- Measures taken to ensure to persons with disabilities, access on an equal basis with others to the physical environment (including the use of signal indicators and street signs), to transportation, information and communications, (including information and communications technologies and systems) and to other facilities and services provided to the public including by private entities, both in urban and in rural areas according to Article 9, paragraphs 2 (b) to (h), of the Convention;
- Technical standards and guidelines for accessibility; as well as on the auditing of their fulfilment and sanctions for noncompliance; and whether resources obtained by means of money sanctions are applied to encourage accessibility actions;
- The use of public procurement provisions and other measures that establish compulsory accessibility requirements;
- The identification and elimination of obstacles and barriers to accessibility including from both within the public and the private sector, and national accessibility plans established with clear targets and deadlines.

It is unclear if this will be done in the final UK State Report.

5.5.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other State Parties. These reports were examined to assist in the interpretation of the Convention but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

In its report, **Australia** describes how it has introduced measures which cover access to transport, education, premises and aviation to meet its obligations under Article 9. Each of these areas has its own set of standards developed to ensure that a barrier-free environment is created. In addition, the Australian

Disability Parking Scheme and National Companion Card Scheme have been developed.²¹⁰

In **Austria** regulations have been developed in the areas of construction, e-government, transport and employment to create a barrier-free environment for people with disabilities. In addition, public and employment facilities have been adapted to accommodate people with disabilities, information is to be translated into Braille, sign language interpreters are to be made available and training courses for certain professions have been introduced.²¹¹

In its report on Hong Kong, **China** has aimed to create a barrier-free physical environment for persons with disabilities, which permits their access to all buildings and use of public transports. Hong Kong also aims to support persons with disabilities in the use of information and communication technologies in their daily lives so as to enhance their capacity to lead an independent life. This being achieved through the creation of a subcommittee on access under the Rehabilitation Advisory Committee (RAC), introducing regulations to ensure all buildings and public transport (trams, buses, ferries, airplanes, trains and taxis) is accessible, creating an advisory service on barrier-free facilities, setting out guidelines for information and communication technologies using the distribution of awards for inclusive designs as a way of encouragement, and providing financial assistance to people with disabilities to acquire computers and software. In addition, the government have implemented a number of plans aimed at educating the public and building a statistics database on complaints against accessibility.²¹²

The government of Macao have introduced a set of technical rules and requirements applicable to all public transport and buildings to be constructed by or for public entities. In addition, all public car parks must reserve a number of parking spaces for persons with disabilities.²¹³

With regard to accessibility, Hungary has made a number of changes in recent years. It is now compulsory to eliminate obstacles regarding public services belonging to administration and municipalities. Subtitling and sign language is to be incorporated into certain television broadcasts. Training on creating a barrier-free environment is now available to a range of specialists.²¹⁴

²¹⁰ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 44-51.

²¹¹ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 14-18.

²¹² CRPD/C/CHN/1/Add.1, 'Report to the Committee on the Rights of Persons with Disabilities: Hong Kong' (30 August 2010), at para 9.10-9.56.

²¹³ CRPD/C/CHN/1/ADD.2, 'Report to the Committee on the Rights of Persons with Disabilities: Macao' (30 August 2010), at para 29-34.

²¹⁴ CRPD/C/HUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Hungary' (14 October 2010), at para 50-69.

Within **Tunisia** plans are in place to redesign and to introduce disability friendly signs to public places.²¹⁵ In its shadow report on Tunisia, the International Disability Alliance (IDA) considers the formulation of a national 'accessibility plan' as crucial in eliminating existing barriers and doing so within a reasonable timeframe.²¹⁶

5.5.4. Key policies and programmes in Northern Ireland relevant to Article 9

5.5.4.1. Manufactured goods

No current policy exists in relation to manufactured goods and the provision of accompanying information in an accessible format.²¹⁷ It is noted that under 1(f) of the UNCRPD, the UK has agreed to "undertake or promote research and development of universally-designed goods, services, equipment and facilities as defined in Article 2 of the Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a disabled person, to promote their availability and use, and to promote universal design in the development of standards and guidelines."²¹⁸ It is likely however that any action on this point will be at EU level as commentators such as the Disability Rights Task Force in 'From Exclusion to Inclusion'²¹⁹, recognised that it could be difficult to impose unilateral legal obligations on UK manufacturers to design their products to be accessible. It acknowledges that UK manufacturers operating within the single European market might be placed at a competitive disadvantage and the UK would still have to accept goods not meeting accessibility standards from other EU States. The recent development of the ratification of the UNCRPD by the EU may encourage action in this field.

A number of charities have developed goods with manufactures for disabled people (see for example the RNID and RNIB websites) and work in this area is ongoing, however, these voluntary arrangements are having little impact on the access to everyday goods such as washing machines, mobile phones, microwaves or digital TV because these goods are not in most cases designed accessibly.²²⁰

²¹⁵ CRPD/C/TUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Tunisia' (14 July 2010), at para 74-81.

²¹⁶ CRPD/C/TUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Tunisia' (14 July 2010), at para 74-81.

²¹⁷ ECNI (2009). Response to UK consultation on the European Commission proposal for an Equal Treatment Directive. ECNI:Belfast.

²¹⁸ Article 1(f) of the UN Disability Convention.

²¹⁹ Disability Rights Task Force (1999). From Exclusion to Inclusion, Final Report of the Disability Rights Task Force.

²²⁰ Template letter to Gordon Brown on manufactured goods <http://www.rnib.org.uk>

Manufactured goods was not mentioned as an area of concern separately from the more general access to goods and services in either the PSI report or the ODI Experiences of Disabled People report.

The results from the conference questionnaire, workshop and focus group did not reveal anything in relation to manufactured goods.

5.5.4.2. Physical access

“Accessibility - being able to go places and not be judged as an inconvenience by other users”²²¹.

Physical access is an area which influences many other areas of a disabled person’s life including participation in political, public and cultural life, independent living and personal mobility and has changed significantly from the introduction of the DDA.

“Access has improved since the DDA but still early days”²²².

However, focus group participants and questionnaire respondents commented that much has still to be achieved, especially with regards to awareness and staff training.

“Whilst access to shops is mostly easy enough for people with a disability, especially wheelchairs, to get into -the shops pack goods for sale on the floor. This causes the aisles to be narrower, and it’s like an obstacle course to get around if you are in a wheelchair”²²³.

One participant reported that while attending a local clinic they were not informed by staff that there was not a lift for access to the clinics on the first floor and that they had to go elsewhere at additional expense. The participant commented that **“staff awareness in relation to the access requirements may have been at fault”²²⁴.**

A 2010 Leonard Cheshire Report in England, ‘Rights and Reality’²²⁵, reported 40% of disabled people have experienced difficulties accessing goods and services in the past 12 months. Two in five (40%) disabled people have experienced difficulties accessing goods and services in the last twelve months, with around a quarter of all disabled people (23%) directly identifying their experiences as discriminatory. Leonard Cheshire further

²²¹ Ibid

²²² Ibid

²²³ Comment from a IMNI Conference questionnaire respondent.

²²⁴ Comment from a participant in the 3rd Thematic focus group (Access to information and statistics and data collection) 18/2/2011

²²⁵ Leonard Cheshire Disability,(2010). Rights and Reality; Disabled peoples’ experience of accessing goods and services. Leonard Cheshire Disability: UK

reported that only 9% of those disabled people who had taken any form of action in relation to the discrimination they had experienced reported that the organisation in question had made improvements in its provision of services for disabled people. The Report further commented that 79% of disabled people agree that if they felt a shop had discriminated against them because of their impairment they would tell friends and family about it. Furthermore, 45% of disabled people surveyed confirmed that if they faced too many difficulties accessing a service they would give up trying to use it. Unfortunately there has not been a similar study in Northern Ireland in relation to access into buildings and services to assess the situation.

Statistics or information in Northern Ireland in relation to complaints about accessibility are not centrally available as fulfilment of these duties is not solely inspected by any one public body. Disabled people have a number of other ways to complain including to the service provider directly, through a solicitor, a service regulator or ombudsman, or to an advocacy, advice or voluntary group such as Disability Action²²⁶. Records are sometimes maintained by such groups although there is no consistent system of recording and few publish figures. The main body assisting people with their complaints under the DDA is the Equality Commission; however, as shown by the Leonard Cheshire reporting patterns, it is likely that the ECNI is aware of only a small percentage of those experiencing difficulties and do not routinely publish compliance rates.

Participants commented on the **“lack of incentives and sanctions for organisations and service providers to provide accessibility”**²²⁷.

A 2002 ECNI report²²⁸ found that, respondents within the retail (62%) and the finance (64%) sectors were more likely to be aware of the DDA than those in the leisure and entertainment (48%) sector. At least two thirds of businesses in the retail (60%) and finance (63%) sectors were aware that the DDA applied to their business compared to only 50% of service providers in the leisure and entertainment sector. Less than half of respondents in the retail (48%) and leisure and entertainment (45%) sectors compared to the finance sector (56%) were aware that the Equality Commission NI has enforcement powers in relation to the DDA.

Moreover, a 2008 ECNI²²⁹ survey found that unprompted awareness of the various items of equality legislation including disability related legislation was

²²⁶ e.g. in 2009 11.9% of reports to Disability Action’s advocacy service were about accessibility issues, the joint highest figure along with Respect for Privacy and Education.

²²⁷ Comment from IMNI Conference questionnaire respondent

²²⁸ ECNI (2002). Knowledge And Awareness Of The DDA Amongst Service Providers. ECNI:Belfast

²²⁹ SMR (2008). Satisfaction of employers and service providers with business support provided by the Equality Commission. ECNI: Belfast (not published)

higher amongst public sector than private sector organisations. As discussed the current system will not allow for the auditing of the fulfilment of the accessibility duties as required by the UNCRPD and other methods such as regular surveys and proactive sector evaluations may be required.

The Leonard Cheshire report suggests conducting a formal review examining the effectiveness of the law and how disabled people's access to their rights in this area can be improved. This review should inform the development of future guidance and regulations, and examine in detail any areas where future extension or adjustment of the law may be necessary.

5.5.4.3. Internet based information²³⁰

5.5.4.3.1. Definitions

Information and Communication Technologies (ICT) play an essential role in supporting daily life in today's digital society. They are used at work, to stay in touch with family, to deal with public services as well as to take part in culture, entertainment, leisure and political dialogues.

e-Inclusion aims to ensure that "no one is left behind" in enjoying the benefits of ICT. E-Inclusion means both inclusive ICT and the use of ICT to achieve wider inclusion objectives. It focuses on participation of all individuals and communities in all aspects of the information society. E-Inclusion policy, therefore, aims at reducing gaps in ICT usage and promoting the use of ICT to overcome exclusion, and improve economic performance, employment opportunities, quality of life, social participation and cohesion.²³¹

e-Accessibility includes computer accessibility; approaches are essentially based on inclusion and the social model of disability as it applies to information technology goods and services; the 'Design For All' principle, also called universal design or inclusive development in other fora, means availability of adequate assistive technology.²³²

Another term associated with this area of work is **media literacy**. Ofcom's definition of media literacy is "the ability to use, understand and create media and communications".²³³

²³⁰ The research team would like to acknowledge the contribution of the Disability Action Marketing Team in supplying information for this section and the forthcoming Disability Action Briefing Paper on 'Digital Inclusion – People with Disabilities'

²³¹ http://ec.europa.eu/information_society/activities/einclusion/index_en.htm

²³² http://en.wikipedia.org/wiki/Digital_inclusion.

²³³ http://stakeholders.ofcom.org.uk/market-data-research/media-literacy/medlitpub/medlitpubrss/ml_adult08/

Digital Participation, the Digital Britain report of June 2009²³⁴ set out its definition of digital participation as follows: “Increasing the reach, breadth and depth of digital technology use across all sections of society, to maximise digital participation and the economic and social benefits it can bring”.

5.5.4.3.2. Information

The focus groups revealed that access to information via the internet was an area of concern to both disabled people and representative groups. The Employers Forum on Disability²³⁵ in 2007 commented that 71% of UK disabled people who use the internet use it to find information on goods and services. Access to information can also be via websites and these are important to disabled internet users.

The most recent report in relation to internet access is the Internet Access Quarterly Update 2011²³⁶ which estimated the level of internet use based on the National Statistics Omnibus Survey which interviews a nationally representative sample of about 2000 households in the United Kingdom.

This UK wide report found that groups of adults who were more likely to have never used the Internet included the over 65s, the widowed and those with a disability. The report does not, however, contain disaggregated figures for disabled people in Northern Ireland, nor is there an indication on the website that they are available in alternative formats such as Easy Read. However these figures were supplied to Disability Action from the Office for National Statistics (ONS) and they revealed that participants who reported that they had ‘ever used the internet’ in Northern Ireland was: for DDA defined disability 46.3% (n=134); for people reporting a work-limiting disability 73.3% (n=21); and for no disability 77.4% (n=833). Figures suggest that internet usage amongst disabled people in Northern Ireland is less than the average in the UK for people with a DDA defined disability (UK=63.8%)²³⁷ and for people reporting a work-limiting disability only (UK=88.3%). It is worth noting that the region where people were least likely to have used the Internet was Northern Ireland - where 28.6 per cent had never done so.

Disability Dynamics²³⁸ reported that, people with lower general skills are also likely to have lower IT skills. They may also have less confidence and motivation to gain new skills. Current training provision is often not sufficiently accessible. This can include obvious factors such as training

²³⁴ www.culture.gov.uk/images/publications/digitalbritain-finalreport-jun09.pdf

²³⁵ <http://www.efd.org.uk/disability/accessible-websites>

²³⁶ Internet Access Quarterly Update 2011, Q1, Office for National Statistics, May 2011, <http://www.statistics.gov.uk/articles/nojournals/internet-access-q1-2011.pdf>

²³⁷ <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672>

²³⁸ disabilitydynamics.co.uk/Papers.../Digital_divide_and_disabled_people.doc

venues, equipment and software but also more subtle barriers such as trainers with limited understanding of the needs of disabled people plus the delivery styles and materials of the training itself. The language of IT technology can present its own barrier with new concepts and a plethora of acronyms. Disability Dynamics²³⁹ further reported that it has been estimated that the reading age of some 50% of the (UK) population is that of a 14 year old. Disabled people are likely to have at least a similar proportion. It further comments that while disabled people tend to use the internet in much the same way as the general population, their usage rates are about 25% lower, less frequent and less recent.

In 2010 the UK Government Published the National Plan for Digital Participation recognised that more needs to be done to increase the digital participation of people with disabilities.²⁴⁰

The Consumer Expert Group (CEG) was asked in the Digital Britain Report to report on the specific issues facing disabled people using the Internet. The report suggested there were a number of issues which affect disabled people and discourage them from using the Internet²⁴¹. These issues fall into the same broad categories as those reported by other people, i.e. motivation, lack of skills and confidence and managing risks of using the internet.

The report also shows that people with certain disabilities face issues that are very specific to their disability, such as the complexity and cost of access technology and the lack of easily understandable information and training that addresses their needs.

The National Plan for Digital Inclusion outlined some key areas to ensure the digital participation of people with disabilities. These included:

- Government should ensure that products and services are usable and accessible for older and disabled people;
- Industry should ensure that specific products and services to support internet use are tailored to the needs of the very old and people with disabilities. This help can be anything from making stores more user friendly, developing more usable and accessible products and services, to offering more intensive follow up support;
- Government should close down publicly funded websites that consistently fail to meet its own web accessibility guidelines.

²³⁹ Ibid

²⁴⁰ Department for Business Innovation and Skills (2010). The National Plan for Digital Participation, Department for Business Innovation and Skills:UK

²⁴¹ http://www.culture.gov.uk/reference_library/publications/6378.aspx

5.5.4.3.3. Accessibility of government websites

The accessibility of government sites has been questioned by researchers. Kuzma comments in a 2009 report²⁴² that “several studies have tested the level of web site accessibility for UK sites and found few meet accessibility requirements for their disabled users”. In 2005, the e-Government Unit of the UK Cabinet Office found that “97 percent of official sites were unusable by disabled people, largely because they ignored well-known techniques for making data accessible” (BBC News, 2005). Only three percent of the sites that were studied passed basic W3C accessibility guidelines. Another survey in 2008 by the UK Public Accounts Committee found that in the past six years the quality of government web sites has only improved slightly and one in six has actually deteriorated, and one-third of sites failed to meet the Cabinet Office’s accessibility standards (Steward, 2008). Kuzma²⁴³ found that the vast majority of the websites of Westminster MPs did not comply with DDA legislation.

Research on the effectiveness of the disability duties in December 2009²⁴⁴ examined the websites of 21 public authorities in Northern Ireland examining compliance with ECNI guidance that a copy of the disability action plan and annual progress report should be made available on public authorities’ websites and they should ensure their websites are accessible to disabled people. The research reports that discussion with disabled people and their representatives highlighted a lack of accessible formats not just in relation to disability action plans, but more widely and that this creates barriers to participation.

Information from a focus group of representatives from voluntary organisations and disabled people held for this research reported that they had found some government websites inaccessible; problems were reported with the inability to change fonts, broken or incorrect links, no search boxes, and the inability to change colours. Participants also reported that some websites did not work with the technologies used by disabled people, while other reported the absence of text phone numbers on a number of sites. Participants commented that accessibility requirements varied with the disability of the person. Form filling online was reported as a problem by participants as they could not resize forms. It was also commented that signposting was poor on many websites and that there was little logic in their layout. It was further reported that incorrect information was given in websites, for example incorrect phone numbers. One participant, for

²⁴² Kuzma, Joanne M., (2009) ‘Regulatory Compliance and Web Accessibility of UK Parliament Sites’, (2) Journal of Information, Law & Technology (JILT)

²⁴³ Ibid

²⁴⁴ ECNI (2009) Effectiveness of the Disability Duties, Review Report. ECNI

example, said that some websites claimed that certain leisure centres were fully accessible but, in reality, access was more difficult²⁴⁵.

The UK Cabinet Office (Europe-wide survey, 2006) conducted a 2005 survey of 436 European public-service web sites, and found that only 3% met full conformance with WCAG guidelines. The results showed four common errors that were prevalent among most sites. The dominant issue was the failure to provide alternative text (alt tags) for non-text elements, which was the same primary problem found in the DRC study. The survey results also showed problems with frameset technology, the omission of frame titles and failure to provide a no-frames alternative. Finally, sites often used JavaScript, which sometimes fails to work with certain assistive technology. In 2007, a study of 468 UK council web sites found that only two met the accessibility level required by government legislation (Local authority website, 2007) reported in Kuzma.²⁴⁶

5.5.4.3.4. The European perspective

Since the Lisbon Agenda was launched in 2000, the EU has had an Information and Communication Technology (ICT) strategy in place.²⁴⁷ The i2010 initiative has three streams or 'pillars':

- The completion of a single European Information Space;
- Strengthening innovation and investment in ICT research;
- Achieving an inclusive European Information Society.

The third pillar, e-Inclusion, is intended to promote an inclusive European information society, and e-Accessibility is a strong theme within this strand.

The European Disability Forum (EDF) is calling for a binding-legislation²⁴⁸ (i.e. a directive). The reasons for this call are listed below:

- non-binding instruments haven't proved their effectiveness to deliver e-accessibility;
- it would be in line with the provisions of the United Nations Convention on the Rights of Persons with Disabilities, which include accessibility of information and communication technologies and systems (article 9), access to information (article 21) and television programmes (article 30);

²⁴⁵ Comments made by participants at the Thematic Focus Group on 'Participation in political and public life'. 26/1/2011

²⁴⁶ Kuzma, Joanne M., (2009) 'Regulatory Compliance and Web Accessibility of UK Parliament Sites', (2) Journal of Information, Law & Technology (JILT)

²⁴⁷ http://www.rnib.org.uk/professionals/softwareandtechnology/softwareaccesscentre/lawsstandards/Pages/europe_accessibility.aspx

²⁴⁸ http://www.edf-feph.org/Page_Generale.asp?DocID=13854&thebloc=18320

- the 2007 “measuring e-accessibility study” demonstrates an overall lack of progress in Europe and the market is not delivering e-accessibility to the European consumers;
- not achieving e-accessibility would have a deep social effect, increasing costs of social protection systems and generating extra costs for the support of persons with disabilities and their families;
- it results in a loss of human capital of disabled workers and thus in a general loss of productivity;
- the general public will also benefit from e-accessibility measures.

5.5.4.3.5. Northern Ireland

The National Plan for Digital Inclusion report considers how the plan is to be implemented in the devolved regions.

In Northern Ireland, the Digital Participation Hub replaced the Northern Ireland Media Literacy Network and brings together organisations and individuals in Northern Ireland with an interest in, or remit for, Digital Inclusion, Digital Life Skills and Digital Media literacy.

‘The Hub will develop an action plan to promote digital participation in Northern Ireland with the aims of getting people online, promoting access to high level digital skills and supporting the digital economy’²⁴⁹.

It is the researchers understanding that the Hub was facilitated by Ofcom, however, as the role is no longer within the remit of Ofcom’s activities it is believed that the University of Ulster is currently facilitating the group.

In a written answer in May 2010²⁵⁰ the Minister for Finance and Personnel was asked if he was working with the Minister for Enterprise Trade and Investment on Digital Inclusion. The response to this question is below.

“Minister of Finance and Personnel: Northern Ireland is well positioned with regard to Digital Inclusion - a Digital Inclusion Unit is based within the Delivery and Innovation Division in DFP. The Digital Inclusion Unit is responsible for Digital Inclusion, and focuses on ensuring that citizens across Northern Ireland are capable of accessing new digital services by establishing, funding and operating a number of digital support projects.

A key part of this involves collaboration and consultation with DETI and other Departments. The DFP and DETI Ministers consulted on a response to the Minister for Digital Inclusion in Westminster on the subject of “Delivering Digital Inclusion – An Action Plan for Consultation”. Also, The

²⁴⁹ Website of Trail (Translating Research and Innovation Lab, University of Ulster at <http://trail:Ulster.ac.uk/2010/04/New-digital-participation-consortium-launched-in-uk/>

²⁵⁰ <http://www.niassembly.gov.uk/qanda/2007mandate/writtenans/2009/100521.htm> (AQO 1236/10)

Rt Hon Stephen Timms MP, in his capacity as Minister responsible for Digital Britain, recently published the "National Plan for Digital Participation". The responsibility for developing the Plan in Northern Ireland rests with the NI Digital Participation Hub which includes representatives from the public, private, voluntary and community sectors including both DFP and DETI.

DFP officials will continue to work with Minister Foster's DETI officials, were required, to enable the implementation of the action plan and relevant digital inclusion initiatives".

In an article in Agenda NI²⁵¹ in November 2010 the Department for Finance and Personnel (DFP) states that Digital Inclusion Unit aims to get 78% of the adult population online by 2014, which would be an increase of 14%. However, there does not appear to be any clear government strategy on how this is to be achieved.

This article also highlights that 90% of new jobs require computer skills and most employers advertise jobs online. The Promoting Social Inclusion (PSI) Report on Disability²⁵² does not have a specific chapter on digital inclusion but a number of the issues are recognised in different chapters. The section on Supportive Technology and Equipment in Chapter 6 and Chapter 9 on Information and Communication make reference to the need for assistive technology to be available to disabled people and a need to improve the accessibility of information. However, the Northern Ireland Executive has yet to respond to the report which was published in December 2009.

Disability Action is aware of a number of projects that have been undertaken by organisations and has also developed its own programmes in the past. Whilst a majority of these projects have demonstrated the benefit of the support given they have only been able to reach small numbers of people. These projects are important to support those to overcome specific barriers such as access to assistive technology and providing accessible learning environments. Projects are often funded on a short term basis and rely on volunteers or corporate social responsibility programmes of commercial organisations.

As reported above in the paragraph on Information (5.5.4.3.2.2 above), the Internet Access Quarterly Update 2011²⁵³ commented that fewer disabled people in Northern Ireland reported having ever used the internet, less than the average in the UK.

²⁵¹ www.agendani.com/digital-exclusion-to-inclusion

²⁵² OFMdFM (2009). Report of the Promoting Social Inclusion Working Group on Disability. OFMdFM: Belfast

²⁵³ Office for National Statistics, (2011) Internet Access Quarterly Update (2011) Q1, Office for National Statistics:UK <http://www.statistics.gov.uk/articles/nojournal/internet-access-q1-2011.pdf>

Ofcom's 2010 report on Digital Participation,²⁵⁴ while not supplying disaggregated figures for disabled people in Northern Ireland, reported 36% of non disabled people and 35% of disabled people in the UK use the internet to look up government or council websites²⁵⁵, perhaps indicating the importance of the internet in accessing services for people with disabilities. The Employers Forum on Disability²⁵⁶ in 2007 commented that 71% of UK disabled people who use the internet use it to find information on goods and services. However focus group participants for this research reported that they had particular problems in receiving responses from website enquiries when call centres were the accepted method of contact, especially in regard to the cancellation of services via e-mail.²⁵⁷

The Information Strategy and Innovation Division (ISID) of the DFP is the central design authority. The ISID website²⁵⁸ comments that it, 'ensures that the IT and information resources are continually optimised to provide best value for money and in turn to improve operational effectiveness and efficiency. This includes the development of policies, strategies, standards and guidelines for IT, information management and information assurance. Information assurance is of the highest priority and ISID provides leadership on this key aspect for the entire NICS'.²⁵⁹ The current Digital Inclusion policy dates from 2003²⁶⁰ and there are plans to replace it. The authors of this research were advised by the ISID that consultation with Disability Organisations will be made in relation to the new Digital Inclusion policy as per government guidelines on consultations but were unable to give any details of this.

The ISID is responsible for the NI Direct Programme, which aims to improve and simplify access to Government Services by citizens. NI Direct aims to provide the citizen with information; to allow the citizen to undertake transactions; and to put the citizen in touch with the correct government

²⁵⁴ Ofcom (2010). Digital Participation (2010) Metric Bulletin (July) using data from Ofcom's quarterly survey of take-up and trends (the 'Technology Tracker')10, and from Ofcom's Media Literacy survey11. Data from the quarterly survey is from January – February 2010, while data from the Media Literacy survey is from two waves conducted in the spring and autumn of 2009. See: <http://stakeholders.ofcom.org.uk/binaries/research/media-literacy/digi-participation/2010-metrics/metrics-bulletin-2010.pdf>

²⁵⁵ Ofcom (2010) Digital Participation 2010 Metric Bulletin (July):. Ofcom: UK <http://stakeholders.ofcom.org.uk/binaries/research/media-literacy/digi-participation/2010-metrics/metrics-bulletin-2010.pdf>

²⁵⁶ <http://www.efd.org.uk/disability/accessible-websites>

²⁵⁷ Comment from participants at the Thematic Focus Group on Participation in political and public life on the 26/1/2011

²⁵⁸ <http://www.dfpni.gov.uk/index/technology-and-innovation/information-strategy-and-innovation-division.htm>

²⁵⁹ <http://www.dfpni.gov.uk/index/technology-and-innovation/information-strategy-and-innovation-division/isid-about-us.htm>

²⁶⁰ http://www.dfpni.gov.uk/digital_inclusion_strategy_2003-2.pdf

office, dealing effectively with at least 50% of enquiries at the first point of contact. This aim makes accessibility to websites and digital inclusion crucial for disabled people in the future. It was noted by the researchers that the contact details for the ISID do not include a text number.

NI Direct is now moving from the pilot phase to full implementation, operating a single citizen-facing website and a multi-channel contact centre using the 101 telephone number. Information from a focus group of representatives from voluntary organisations and disabled people held for this research reported that one fully accessible centralised website was preferred by participants.²⁶¹

ISID is not aware of how many sites have been evaluated with regards to their accessibility and the research has not revealed any published research into the level of compliance of NI Government websites.²⁶² Some limited research has been carried as part of research into disabilities duties²⁶³ and is reported at 7.5.6.3 above. However in the absence of substantive research, it can be reasonably assumed that the situation here is similar to GB.

This raises interesting questions in relation to legal enforcement. Although sites should be designed to adhere to DDA law and industry guidelines, there are many sites, such as the sites in Kuzma's²⁶⁴ 2009 UK MP study where this has not been achieved.

As reported before, the primary enforcement body for the DDA in Northern Ireland is the Equality Commission for Northern Ireland. The DDA is civil law; therefore, it is for disabled people who believe that they may have been discriminated against to bring a case forward. Peck²⁶⁵ reports that while there have been general disability cases regarding DDA law, only a few cases have been brought regarding web accessibility. However there have been some successes, e.g. a Sheffield woman won a disability case against the UK Department for Work and Pensions (Law Centres Federation, 2009).²⁶⁶

In order to increase the level of web accessibility in the UK, organisations such as the RNIB, are taking an active role in promoting compliance with legal mandates. However as Kuzma comments there are other forms

²⁶¹ Focus group held in Disability Action on the 18/2/11 on Access to information and Article 31 on Statistics and Data Collection

²⁶² Information from meeting with ISID staff on the 17/2/11

²⁶³ ECNI (2009). Effectiveness of the Disability Duties: Review report. ECNI: Belfast

²⁶⁴ Kuzma, Joanne M., (2009) „Regulatory Compliance and Web Accessibility of UK Parliament Sites, *Journal of Information, Law & Technology (JILT)*, (2).

²⁶⁵ Peck, N (2003), „Interview – Julie Howell, Royal National Institute of the Blind , SitePoint.com, October 25, 2003, [online] <<http://www.sitepoint.com/article/national-institute-blind/>>

²⁶⁶ Reported in Kuzma, Joanne M., „Regulatory Compliance and Web Accessibility of UK Parliament Sites, 2009(2) *Journal of Information, Law & Technology (JILT)*,

of disability, both cognitive and physical, that can affect users ability to successfully access web pages, and these users may not have a group that promotes accessibility for their impairment. Kuzma argues that rather than a piecemeal approach by disability organisations a centralised government coordinated policy with enforcement is a better approach to aid all disabled people²⁶⁷. Participants in the focus groups for this research suggested that the voluntary sector lead the research and audits on web-sites and that disabled people should be involved, however they recognised that funding will be problematic²⁶⁸.

Paciello (2000, p19) reported that one of the main reasons for poorly designed web sites is 'lack of awareness among web developers'.²⁶⁹ He estimated that 50 percent of the poor design is because developers were unaware of legal and industry requirements for effective accessibility. Kuzma²⁷⁰ comments that it is recommended that, 'more conferences, education and workshops be made available to developers in order to raise their awareness and to provide better level of accessibility and that the government take a stronger role in policing their own sites and creating stronger enforcement. In addition, more education should be provided to encourage web designers to understand current DDA law, industry guidelines and the requirements of the UNCRPD when creating new sites'²⁷¹. Participants in a focus group of representatives from the voluntary sector and people with disabilities held during this research expressed that people with disabilities should be involved in the design and regular testing of these sites²⁷².

A recent good practice example of public bodies engaging with the disability sector to improve access to information for people with disabilities was by the Police Ombudsman's office. They reported in their annual progress under Section 75 of the NI Act 1998 and Section 49A of the Disability Discrimination Order (DDO) 2006 to the ECNI that they had 'reviewed aspects of it communication process with Disability Action in order to improve access to information for people with disabilities. As a consequence of that review the Office has taken action to establish a distinct tab on the website providing information for people with disabilities. In addition, the

²⁶⁷ Ibid

²⁶⁸ 262 Comment from participants in a Thematic Focus Group on Participation in political and public life, 26/1/2011.

²⁶⁹ Paciello, M. (2000), *Web Accessibility for People with Disabilities (R & D Developer Series)*, CMP Books

²⁷⁰ Kuzma, Joanne M., (1990) (2) *Regulatory Compliance and Web Accessibility of UK Parliament Sites*, *Journal of Information, Law & Technology (JILT)*,

²⁷¹ Ibid

²⁷² Comment from participants in a Thematic Focus Group on Participation in political and public life, 26/1/2011.

Office is exploring the prospect of providing an “easy read” version of our information leaflet for complainants”.²⁷³

5.5.4.4. Staff attitudes and training

Another area of concern from the focus groups is the attitudes and training of first line staff with respect to the accessibility duties.

Disabled people experience barriers to accessing everyday services such as transport. These barriers are not just about physical access to buildings and vehicles. For many people poor service and the attitudes of staff providing services can be a major deterrent to using services.

IMTAC reports²⁷⁴ in relation to transport, that feedback it has had from disabled people indicates that whilst physical access to transport is getting much better the attitudes of those providing services remains a key barrier.

Policy 6 of the DRD Accessible Transport Strategy (ATS)²⁷⁵ requires organisations involved in the provision of transport services to provide appropriate training for staff around meeting the needs of disabled people and the Department of the Environment has also indicated that as part of changes to taxi regulation here training for drivers in meeting the needs of disabled passengers will become mandatory.²⁷⁶

The UNCRPD comments that under Article 9 (2) (c) that State Parties are required to provide training for stakeholders on accessibility issues. While there is clear evidence that information in relation to good practice and outreach training is available (for example, ECNI's 'Reaching out' training), there is little publically available and/or accessible information in relation to the training service provider staff receive, or evaluations of its effectiveness. It is reported that in the majority of Public Sector Disability Action Plans, Disability Awareness training is ongoing, however, there is little monitoring of the outcomes.²⁷⁷ This makes it difficult to comment on the effectiveness of the training provided by Government departments and agencies.

5.5.5. Results from the questionnaire and focus groups

Forum participants and questionnaire respondents reported continuing problems with access to buildings and services and these are fully listed in

²⁷³ ECNI (2006) ECNI report on the Police Ombudsman's office, Public Authority 2009 - 2010 Annual Progress Report on Section 75 of the NI Act 1998 and Section 49A of the Disability Discrimination Order (DDO) 2006

²⁷⁴ IMTAC (2009) Disability training – Good practice guidelines for transport providers

²⁷⁵ The Accessible Transport Strategy (2005) is available online at www.drdni.gov.uk

²⁷⁶ IMTAC (2009) Disability training – Good practice guidelines for transport providers

²⁷⁷ McIlWhan R, Roger S and Bridge S. (2009) Evaluating the effectiveness of the Disability Discrimination (NI) Order 2006 Duties: ECNI: Belfast

the Appendices to this report. However a selection are listed in the previous section and below:

One participant who was a political party member commented on the lack of access to ramps in his local office. A number of participants commented on the access restrictions into Stormont in that, there was no access though the heavy double doors inside nor through the front door adding that they had to access **“in through the back door”**²⁷⁸. Another participant asked **“how many offices are accessible?”**²⁷⁹

“Accessibility issues are preventing participation, especially access to buildings, to amenities such as accessible taxis, toilets and many other services”²⁸⁰.

5.5.5.1. Access to information

Accessibility was the third highest key area for respondents in the conference questionnaire, however, when this was further explored during the conference workshop and the scoping focus groups it became clear that access to information was a primary factor in this rating.

5.5.5.2. Access to printed information

The focus groups revealed that access to information was an area of concern to both disabled people and representative groups. This has been highlighted by recent studies by the RNID and BDA²⁸¹ and the ECNI²⁸² and as previously reported in Article 5 it is acknowledged by the Health service that “people with a sensory impairment such as deafness or blindness face difficulties in accessing information about HSC services”.

In Northern Ireland the DDA (1995) obliges all providers of goods and services to take reasonable steps to enable disabled people to use their services. In practice this means that all companies, public bodies and charities need to make all of their printed information available in accessible formats wherever it is reasonable to do so. Access to information can also be via websites and there is an increasing movement to place information on the web due to cost and ease of access for the majority of the population.

²⁷⁸ Comment from participants in a Thematic Focus Group on Participation in political and public life, 26/1/2011.

²⁷⁹ Ibid.

²⁸⁰ Comment from a participant in the 2nd Thematic focus group (Participation in political and public life) 26/1/2011.

²⁸¹ RNID and BDA (2009). Access to Public Services for Deaf Language users

²⁸² ECNI (2007). Formal Investigation under the Discrimination legislation to evaluate the accessibility of Health Information in Northern Ireland for people with a learning Disability, June 2006 to December 2007. ECNI: Belfast

Focus group respondents reported a number of problems with the current systems including, staff attitudes and training (discussed below), the immediate availability of information in printed format, confusion between easy read and large print, a lack of help lines, signposting to advice and information, information about government systems (who they should contact or where the information is held) and of jargon free information in accessible formats. Text numbers were often not on information leaflets and there was a lack of coordination in relation to the accessible information available. Information was available from one source but the information journey was blocked by a lack of accessible information from another source. Participants reported that they were not being generally consulted in relation to the formats in which information was available (format included colour, layout, size and language).

When the participants were asked how the situation could be improved they commented that greater co-ordination was required and that all stakeholders including disability groups need to cooperate and learn best practice from each other. They suggested that information directly concerning disabled people should be centralised.

Participants recognised that disability is a diverse issue and responsibility crosses departments but commented that the coordination process should be centralised. Crucial to coordination is consultation with disabled people at an early stage and at the action plan stage. It was commented that there should be considered planning and coordination and not knee jerk reactions and quick fixes.

As reported in Article 8, sign-posting information should be available in places people with disabilities frequent, including Doctor's surgeries, hairdressers, post offices and supermarkets.

It was commented that government should look at examples of best practice elsewhere although a group participant commented **"research information on disability does not appear to be reaching policy makers"**.²⁸³ Scotland was given as an example in relation to the setting of standards for accessible communication i.e. easy read.

Participants commented that there was a need for greater advocacy support (in accessing information).

²⁸³ Comment from a participant in the 3rd Thematic focus group (Access to information and statistics and data collection) 18/2/2011

5.5.4.3 Internet Access

Participants reported that the attitudes of staff towards disabled people were a primary barrier to them obtaining the information they required. Staff did not give them the extra time they needed and many participants reported examples of staff putting phones down or asking why they wanted the information. Participants reported that this was reducing their ability to participate in society.

Participants commented that negative attitudes towards disabled people were still entrenched at all levels.

A particular problem was reported by the RNID representative in that many government bodies, banks, etc. would not accept third parties contacting them on the telephone on behalf of a deaf or hard of hearing persons even after the reason was explained to the member of staff.

In relation to front line staff attitudes towards disabled people, it was commented that more help and patience with disabled people by staff would assist people in accessing information, as would an acknowledgement of the right of disabled people to access this data.

5.6. Article 10: Right to Life

Article 10 - Right to Life

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 10 is worded in very strong terms, which is unsurprising given the right it seeks to address. It 'reaffirms' the existing right to life and imposes an obligation on State Parties to take 'all necessary measures' to ensure its effective enjoyment by people with disabilities on an equal basis with others.

Article 10 does not 'flesh out' the obligation in a manner similar to that of Articles 8 or 9. This clearly leaves the range of policy and programme measures to protect this right open and potentially very broad indeed. The best way to articulate the content of the obligation in greater detail is to outline the generally recognized context of the right to life and then give examples of policies and programmes which would contribute to realizing this right for people with disabilities.

5.6.1. Consideration of other UN human rights treaties

With respect to the right to life set out in Article 6 of the International Covenant on Civil and Political Rights (ICCPR), the Human Rights Committee considers that States Parties should take measures not only to prevent and punish deprivation of life by criminal acts, but also to prevent arbitrary killing by their own security forces.²⁸⁴ Moreover, States Parties should take specific and effective measures to prevent the disappearance of individuals and to establish effective facilities and procedures to investigate thoroughly cases of missing and disappeared persons in circumstances which may involve a violation of the right to life.²⁸⁵

The Committee has stated that the expression “inherent right to life” cannot properly be understood in a restrictive manner, and that the protection of this right requires that States adopt positive measures. In this connection, the Committee considers that it would be desirable for States Parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics.²⁸⁶

5.6.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 10 in the guidelines on treaty-specific documents to be submitted by States Parties under Article 35, paragraph 1, of the Convention on the Rights of Persons with Disabilities, the Committee on the Rights of Persons with Disabilities requires that the report should include whether persons with disabilities are being subject to arbitrary deprivation of life. This clearly requires a research and/or monitoring programme(s) and policy(-ies) sufficient to enable State Parties to report on this very specific point. As previously reported the aggregation of statistics within the health service may cause difficulties when examining the comparative success of life saving treatment outcomes for disabled people.

5.6.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other State Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They

²⁸⁴ Human Rights Committee (1982) General Comment 6: The Right to Life, at Para 3.

²⁸⁵ Human Rights Committee (1982) at Para 4.

²⁸⁶ Human Rights Committee (1982) at Para 5.

should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

With respect to Hong Kong, **China** has reported that the Hong Kong government offers a range of preventive, supportive and remedial programmes and services through the Integrated Family Service Centres, Integrated Service Centre, medical social services units in hospitals and clinics, school social work service, integrated children and youth service centres, as well as outreaching social work teams, in order to help young people, families and other vulnerable groups, including persons with disabilities with a risk of suicide to better cope with adversity and strengthen their support network. Specific measures include operating a Suicide Crisis Intervention Centre to provide outreach and counselling services, and the launch of the publicity campaign 'Strengthening Families and Combating Violence' which incorporates suicide.²⁸⁷

In its shadow report on Tunisia, the International Disability Alliance (IDA) calls for steps to be taken to effectively investigate deaths in the home and institutions (residential institution and hospitals) relating to persons with disabilities as part of ensuring Article 10 of the UNCRPD is protected.²⁸⁸

5.6.4. Key policies and programmes in Northern Ireland relevant to Article 10

This research has not found any policies in Northern Ireland which specifically refer to the rights of disabled people over and above the general rights of non disabled people which are contained in statute, in the ethical codes of the medical professions, in codes of practice governing behaviour of organisations and individuals and in equality legislation to ensure non discrimination.

Many factors have a negative impact on the enjoyment of Article 10 rights.

This report shall briefly illustrate these points by referral to suicide prevention strategies and health care decisions in order to stimulate a discussion which is not currently taking place.

5.6.4.1. Health care decisions

There is some evidence from non UK jurisdictions which suggests disability, especially mental illness, is linked to a lesser chance of involvement with life

²⁸⁷ CRPD/C/CHN/1/Add.1, 'Report to the Committee on the Rights of Persons with Disabilities: Hong Kong' (30 August 2010), at para 10.1- 10.8.

²⁸⁸ International Disability Alliance, 'Submission on List of Issues for Tunisia: Committee on the Rights of Persons with Disabilities', October 2010, at 3.

saving transplants schemes, this is due in part to the psychosocial assessment of organ candidates e.g. Orentlicher 1996²⁸⁹ (e.g. will disabled people comply with behaviour requirements such as taking medication) or in hip replacement for Down's syndrome patients.²⁹⁰ Orentlicher commented that when organ programmes deny access to a noncompliant person, it is denying an organ on the basis of an eligibility criterion that is more common in persons with coexisting disabilities such as mental illness.

Savulescu 2001²⁹¹ reports on the independent inquiry into Paediatric Cardiac Services at the Royal Brompton Hospital and Harefield Hospital which investigated the allegation that children with Down's syndrome were discriminated against. It was alleged (but not proven) that children were inappropriately "steered away" from surgery for heart defects because they had Down's syndrome. The inquiry recommended that: "The Trust's policies confirm clearly that people with a disability are entitled to, and will be accorded ... the same rights of access to services as those without a disability; and that consultants should take the lead in implementing policies and influencing attitudes regarding equality of access." Similarly, a principle in the report's model guidance to avoid discrimination is that: "Access to services, and priority for treatment should be determined only on the basis of clinical need." The principle of equality of access is thus equal treatment for equal need. However, Savulescu further comments that equality of access is uncontroversial when there are resources to treat everyone but that equality of access is problematic when resources are scarce.

Within the UK there is evidence that disabled people receive poorer healthcare than non disabled people²⁹² and this is further explored under Article 25. The Disability Rights Commission (DRC) in 2006 carried out a formal investigation into the nature and causes of physical health inequalities experienced by people with mental health issues and/or learning difficulties (term used to describe those with intellectual disabilities) in England and Wales and concluded they are more likely than other citizens 'to experience major illnesses, to develop them younger and die from them sooner'.²⁹³

The British Medical Association last examined the issue in 2007²⁹⁴ and concluded that', "while more comprehensive and robust data are needed on health inequalities, there is evidence that disabled people experience various inequalities in health outcomes when compared to non-disabled people and that access to healthcare services is often inequitable"²⁹⁵. The BMA

²⁸⁹ <http://www.ncbi.nlm.nih.gov/pubmed/8937917>

²⁹⁰ <http://www.ncbi.nlm.nih.gov/pubmed/16532986>

²⁹¹ Savulescu, J. (2001) Down's syndrome, and cardiac surgery: Do we really want "equality of access?" *BMJ* 322 : 875 doi: 10.1136/bmj.322.7291.875 (Published 14 April 2001)

²⁹² <http://news.bbc.co.uk/1/hi/health/104480.stm>

²⁹³ www.drc.org.uk/healthinvestigation

²⁹⁴ BMA (2007) Disability equality within health care: The role of healthcare professionals,

²⁹⁵ *Ibid*, Page 1

report recommended increased participation of disabled people and their representatives with healthcare professionals, awareness raising (including disability champions), recognition in provision that disabled people are not a homogeneous group, training of staff, better monitoring and impact assessments to ensure compliance with disability legislation and better planning for the provision of services to disabled people.

Mencap produced a report; *Death by indifference* (2007)²⁹⁶ in which it highlighted the widespread ignorance and indifference throughout the health care services towards people with a learning disability which they stated amounted to institutional discrimination. They reported that people with a learning disability receive worse healthcare than non disabled people and presented the stories of 6 people whom they alleged died unnecessarily.

Within Northern Ireland inequalities in access to health care is widely recognised, see for example the RNID report 'A Simple Cure'²⁹⁷ and a joint RNID/RNIB/BDA Report 'Is it my Turn Yet?, Access to GP practices in Northern Ireland for people who are deaf, hard of hearing, blind or partially sighted within Northern Ireland'²⁹⁸. These are discussed further under Article 25 and their conclusions are reflected in the DHSSPS 2011 draft action plan.²⁹⁹

Robust data in relation to inequalities in treatment is difficult to find as highlighted by the BMA above, and this is in partly due to the fact that, "HSC data systems do not record all the s75 category information and this means that a lot of the findings are anecdotal and some were based on findings from outside Northern Ireland or from reports produced by representative / stakeholder organisations. In addition, in some cases the sources were fairly dated and the material may no longer be valid".³⁰⁰ The DRC study³⁰¹ commented in relation to learning disability that their figures were determined from area studies rather than through analysis of GP clinical databases as recording of learning difficulty in primary care is poor.

An example of this problem can be found in the area of transplantation in Northern Ireland. Transplant guidelines / policies are held both nationally and at trust level An example of this problem can be found in the area of transplantation in Northern Ireland. Transplant guidelines / policies are held both nationally and at trust level (see for example the renal transplant

²⁹⁶ Mencap (2007) *Death by indifference*

²⁹⁷ <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/research-reports.aspx>

²⁹⁸ <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/research-reports.aspx>

²⁹⁹ http://www.dhsspsni.gov.uk/draft_equality_action_plan.doc

³⁰⁰ DHSSPS (2011) Equality Action Plan, <http://www.dhsspsni.gov.uk/showconsultations?txtid=46900>

³⁰¹ www.drc.org.uk/healthinvestigation

guidelines³⁰²) and these are based solely on clinical assessment including consultation with patients, partners and families³⁰³. Patients are placed on the transplant waiting list by their local consultant physician or surgeon in accordance with nationally agreed criteria. Their names are then notified to UK Transplant for inclusion on the national transplant database. Individual social and psychological needs are also considered during the clinical decision-making process³⁰⁴. The team, however, is also advised that statistics in relation to disability are not recorded at the registration level where gender, age and ethnicity are as they are factors relevant to the process³⁰⁵. The recording of these factors is also noted in the guidelines for renal transplantation under guideline 1.4 which states;

5.6.4.1.1. Guideline 1.4 – Tx: Access to renal transplantation

“We recommend that there must be demonstrable equity of access to deceased donor kidney transplantation irrespective of gender, ethnicity or district of residence. (1A)”³⁰⁶

As disability is not routinely recorded it is difficult, if not impossible, to test the equity of access when on the transplant waiting list for people with non condition related disabilities without a dedicated investigation into the area. This is a disappointing position considering the recommendations of the independent inquiry into Paediatric Cardiac Services at the Royal Brompton Hospital and Harefield Hospital reported in Savulescu 2001³⁰⁷ (above). The research team is advised by the BMA³⁰⁸ that work is currently ongoing at NHS Blood and Transplant on a revision of the selection policies guidelines which will include a section on disability.

With regard to the evidence reported above on the difficulty of access to health services, it is possible that disabled people may find access into the pre-transplant list process difficult, however without research and data on the matter it is impossible to come to any conclusions.

³⁰² <http://www.renal.org/clinical/GuidelinesSection/AssessmentforRenalTransplantation.aspx>

³⁰³ http://www.uktransplant.org.uk/ukt/about_transplants/organ_allocation/liver/national_protocols_and_guidelines/protocols_and_guidelines/adults.jsp

³⁰⁴ http://www.organdonation.nhs.uk/ukt/newsroom/statements_and_stances/statements/equality_of_access_to_donor_organ.jsp

³⁰⁵ Information from recipient transplant team, Belfast City Hospital, May 2011

³⁰⁶ <http://www.renal.org/clinical/GuidelinesSection/AssessmentforRenalTransplantation.aspx>

³⁰⁷ Savulescu, J. (2001) Down's syndrome, and cardiac surgery: Do we really want "equality of access?" *BMJ* 322 : 875 doi: 10.1136/bmj.322.7291.875 (Published 14 April 2001)

³⁰⁸ June 2011

5.6.4.2. Suicide prevention

In Northern Ireland the suicide rate has increased by an alarming 64% in the past decade.³⁰⁹ The primary policy is the Northern Ireland Suicide Prevention Strategy and Action Plan 2006-2011 which seeks to reduce the suicide rate in Northern Ireland.³¹⁰ An examination of the suicide prevention consultation report³¹¹ reveals, “When considering the equality implications of the Promoting Mental Health Strategy and Action Plan the Department considered data from the Health and Social Wellbeing Survey 2001, the Health Behaviour of School Children 1997/98, and Safety First: National Confidential Enquiry into Suicide and Homicide in People with Mental Illness. The Department has revisited the available information, and in particular specific information from the General Registers Office (GRO) relating to suicide. Data on all nine equality groups outlined in the Northern Ireland Act (1998) is not recorded. Information is only readily available for sex, age and marital status. However the full postcode is recorded which allows various geographical comparisons to be made”.³¹² The Department also considered research in sexual orientation³¹³.

Following the consultation the department decided to use a dual approach using a population and targeted approach. The population approach seeks to tackle the issue of suicide in a wider generic context, with actions aimed at protecting the general population of Northern Ireland. The targeted approach seeks to tackle the issue by targeting actions at those within society who are most at risk of suicide, for example, young men and marginalised and disadvantaged groups which it states must be complementary.

The Department considered that the policy should impact positively on the health and emotional wellbeing of the general population and it commented that it considered that as the Strategy and Action Plan did not adversely impact on any of the S 75 groups and therefore a full Equality Impact Assessment was not required.

The report recognises that the policy is most likely to have an impact on gender, age, religion, marital status and sexual orientation and that it will also impact on those from lower socio-economic groups. The report also recognises that due to the limited equality data for deaths recorded by GRO, it is quite possible that there may be differential impact on other equality

³⁰⁹ <http://www.guardian.co.uk/society/2011/mar/16/suicide-rates-northern-ireland>

³¹⁰ http://www.dhsspsni.gov.uk/phnisuicidepreventionstrategy_action_plan-3.pdf

³¹¹ DHSSPS Suicide consultation main report. See: <http://www.newcolin.com/uploads/7b7b01fe-58e2-4222-8385-7220f17ec7e8/Suicide%20Consultion.pdf>

³¹² Ibid, paragraph 2.6 at <http://www.newcolin.com/uploads/7b7b01fe-58e2-4222-8385-7220f17ec7e8/Suicide%20Consultion.pdf>

³¹³ Carolan, F. & Redmond, S (2003) *Shout: The Needs of Young People in Northern Ireland who identify as lesbian, gay, bisexual and or transgender*. YouthNet: Belfast.’ and McNamee, H (2006) *Out on Your Own: An Examination of the Mental Health of Young Gay and Bisexual Men*, The Rainbow Project: Belfast (annex 3, paragraph 2.6)“

groups that have not been analysed such as those with a disability, black and ethnic minority and those with/without dependants.

This recognition raises issues about the uptake of support services by disabled people and the access to material bearing in mind the conclusion in relation to literature and website accessibility in Article 9 and the comments in Article 25.

This research is advised that the policy has been revised (revision covering 2010-2013) with a greater recognition of disability as a risk factor in suicide notably in relation to isolation and post conflict mental illness³¹⁴, although the policy is not yet publically available.³¹⁵

The lack of equality data is also relevant to the ongoing debate in relation to assisted suicide in which a 2011 study by Scope³¹⁶ found 70 per cent of disabled people were concerned that such a reform of the law to allow assisted suicide would create pressure on vulnerable patients to “end their lives prematurely”. The survey for Scope, a leading disability charity, also found 3 per cent of the 500 disabled people questioned in the ComRes poll feared that they would personally come under pressure to commit suicide if the law were changed.

Richard Hawkes, chief executive of Scope, said: “Disabled people are already worried about people assuming their life isn’t worth living or seeing them as a burden, and are genuinely concerned that a change in the law could increase pressure on them to end their life.” The Scope/ComRes survey also disclosed that 56 per cent of disabled people felt the legalisation of assisted suicide would be detrimental to the way that they are viewed by society as a whole.

5.6.5. Results from the questionnaire and focus groups

Surprisingly there were no comments from either the questionnaire or the focus groups in relation to the right to life. Whether the absence of comments was due to a lack of knowledge or debate about the area, or if the matter is too personal to discuss in the research structure used is unknown.

5.6.6. Conclusion

While it is accepted that in general terms disabled people in the UK have the same rights from birth as non disabled people, and are not subject to arbitrary deprivation of life policies, further debate is required. In order to

³¹⁴ <http://www.guardian.co.uk/society/2011/mar/16/suicide-rates-northern-ireland>

³¹⁵ Information from Contact NI May 2011

³¹⁶ <http://www.scope.org.uk/news/poll-on-assisted-suicide>

have this informed discussion, a research and/or monitoring programme(s) to supply the disaggregated information necessary is required. This will allow the State Parties to more fully report on this very crucial Article within the UNCRPD.

5.7. Article 11: Situations of risk and humanitarian emergencies

Article 11 - Situations of risk and humanitarian emergencies

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Article 11 has clear impact on all policies and programmes related to 'situations of risk'. Such situations are non-exhaustively defined as including:

- armed conflict;
- humanitarian emergencies; and
- natural disasters.

The obligation is a strong one in that it requires that 'all necessary measures' be taken to ensure the protection and safety of persons with disabilities. The text of Article 11 does not 'flesh out' the obligation in a manner similar to that of Articles 8 or 9. This clearly leaves the range of policy and programme measures to protect this right open and potentially very broad indeed. In general it requires that policies and programmes explicitly consider the particular needs of people with disabilities in their diversity and include measures which will ensure their protection and safety. Article 11 does not include a 'on an equal basis with others' clause and thus should be read as imposing obligations to take measures for the protection of persons with disabilities in situations of risk which do not necessarily exist for persons without disabilities.

5.7.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 11 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD,

the Committee on the Rights of Persons with Disabilities requires that the report should cover any measures taken to ensure their protection and safety including measures taken to include persons with disabilities in national emergency protocols.

5.7.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from Reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other State Parties. These Reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

The Australian State Report makes clear that the 'National Principles for Disaster Recovery' and all the regional guidelines recognise that successful recovery should support those who may be more vulnerable, such as persons with disabilities. Many of these guidelines are available in a range of formats to make them more accessible to people with disabilities.³¹⁷ The provision of such information in alternative formats can be seen as a necessary means of achieving the aim of Article 11.

In its State Report, Austria states that in the context of disaster relief the Austrian army have been trained to pay particular attention to the special situation of people with disabilities in situations of risk and humanitarian emergencies.³¹⁸

The Spanish State Report explains that the National Civilian Protection School run separate courses which incorporate subjects such as health, immobilisation techniques for the handling and transportation of persons with reduced mobility, aged persons and pregnant women. Classification and sorting techniques which take account of these groups including special circumstances of mental and sensory impairment, and primary and secondary victim assessment techniques which take into account the possibility that an impairment was present before the disaster caused the injury.³¹⁹

³¹⁷ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 53-54.

³¹⁸ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 19.

³¹⁹ CRPD/C/ESP/1, 'Report to the Committee on the Rights of Persons with Disabilities: Spain' (3 May 2010), at para 49-51.

In its role as the Independent Mechanism under Article 33(2) for **Spain**, CERMI has called in their shadow report for alternative and augmentative communication systems, signed language and Braille, for the communication of emergency messages for persons with disabilities to bring policies and programmes in line with Article 11 of the UNCRPD.³²⁰

5.7.3. Key policies and programmes in Northern Ireland relevant to Article 11

'Civil contingencies are largely a devolved function in Northern Ireland. Each Northern Ireland government department is responsible for determining its own policies and practices in relation to civil contingencies, within an overall agreed Framework. The Civil Contingencies Policy Branch (CCPB)³²¹ within the Office of the First Minister and Deputy First Minister (OFMDFM) co-ordinates strategic policy and encourages good practice but has no powers of direction over other government departments.

One of the ways in which CCPB encourages good practice is through the development of guidance documents. These represent agreed statements of policy and good practice. A key document is 'The Northern Ireland Civil Contingencies Framework'³²² which sets out the overall principles of Departmental participation in civil contingencies activities. These principles can also apply by extension from Departments to their agencies and Non-departmental Public Bodies (NDPBs).

As most of the main organisations, which plan for and respond to emergencies in Northern Ireland, are public authorities, the requirements of Section 75 of the Northern Ireland Act 1998 apply to them in respect of their civil contingencies policies and plans. The requirements of the Disability Discrimination Act 1995 will also apply to these organisations and to any private or voluntary sector organisations which are also involved.

Two significant documents are 'Arrangements in Northern Ireland' and 'A Guide to Evacuation in Northern Ireland' (these documents were issued under the CCPB's previous name of Central Emergency Planning Unit, but they remain valid). These documents make reference to the need to take account of persons with disabilities in planning and response. The Northern Ireland Civil Contingencies Framework specifically refers to Section 75 duties in relation to preparing for emergencies and in the provision of public information before and during emergencies. 'A Guide to Emergency Planning Arrangements' has a chapter on the needs of people

³²⁰ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 53-54.

³²¹ The research team is indebted to the Staff of the CCPB for the detailed information provided for this section of the report

³²² <http://www.ofmdfmi.gov.uk/ni-ccf-dec05.pdf>

in emergencies (Chapter 7) and states that "...any accommodation which is planned for use for evacuees, survivors and friends and relatives should have access and facilities for the disabled" . Good practice in planning and using evacuation centres is set out more fully in 'A Guide to Evacuation in Northern Ireland' which was produced by a multi-agency Evacuation Working Group. This guidance also states the importance of ensuring that the needs of people with special needs, including those with disabilities, are met in making plans for evacuation and rest centres.

Civil contingencies functions of Northern Ireland government departments are covered by the wider corporate governance and audit arrangements of each department. This means that where appropriate the department's civil contingencies activities would be included in business plans and that those activities would be undertaken in accordance with all the statutory and non-statutory standards which apply to the department as a whole.

As part of this, a Department's internal audit process would consider its civil contingencies activities, either as part of a thematic study or as an integral part of the delivery of relevant functions. The purpose of the audit would not be to say whether emergency policies and plans would be effective in practice (that is ensured through validation processes such as exercises) but to ensure that civil contingencies arrangements take account of good practice guidance and any relevant statutory requirements'.³²³

5.7.3.1. Provision of public information in an emergency

Where public information is prepared and disseminated in advance of an anticipated emergency or where it is provided as part of a medium to long term response to the impacts of an emergency (for example information about the possible long-term mental health impacts of an emergency and how those affected can access services), the standards for publication would be the same as for any organisational communication. The exact detail of the publication format would be determined by the intended audience but normal practice for general publications is to comply with good practice in the use of accessible formats and to offer alternative formats, such as Braille, on request.

Because of the unpredictability of emergencies it is not possible to pre-prepare communications to cover all circumstances. Good practice guidance on communicating in an emergency, for example in the 'Guide to Emergency Planning Arrangements in Northern Ireland' document³²⁴ involves ensuring that messages are delivered with regard to the needs of the target audience, within the constraints of individual emergency circumstances.

³²³ Section taken from information supplied by the CCPB Autumn 2010

³²⁴ <http://www.ofmdfmi.gov.uk/aguidetoemergencyplanningarrangements.pdf>

The DHSSPS April 2011 standard³²⁵, as an example of internal departmental Emergency Planning guidance, comments that:

“...the contingency plans should take account of the statutory obligations arising from section 75 of the Northern Ireland Act 1998, the Human Rights Act 1998 and the Disability Discrimination Act 1995 and should include facilities in Emergency Support Centres for disabled people, special foods compatible with religious beliefs and printing of advice leaflets in appropriate languages etc. However, it needs to be recognised, in an emergency situation when time is limited and resources are stretched, it may be necessary for the HSC and the emergency services to prioritise actions and resources which will provide the greatest benefit for the greatest number of people. All sections of the emergency planning controls assurance standard have been revised and updated for 2010 / 2011 ”.³²⁶

The Consumer Council 2011 report³²⁷ on the 2010 water crisis, ‘Left high and dry’ examined the effects on disabled consumers of emergency planning. Specific detail was supplied on the effect of the crisis following contact with the Consumer Council in February 2011 and they reported that many of the difficulties expressed by a focus group of disabled people were the same as many others, including: lack of planning; a lack of (or sometimes wrong or poor quality) information from NI Water; not being able to contact NI Water on the telephone; and NI Water’s website struggling to cope. Where there was particular difficulties (and in many ways these were shared by older consumers as well) was in the provision of alternative supplies. In particular: NI Water not knowing that the consumer had extra needs and the consumer not knowing about NI Water’s customer care register; no bottled water being delivered; not knowing where the water depots to collect water were located; the depots not being accessible (not on bus routes, not being lit at night, long queues and long waits); and not being able to carry heavy loads of water.

The Consumer Council added that they had previously made the suggestion that NI Water should consult with representative groups to develop and promote the services provided by it consumers who need extra help. The Consumer Council would support the idea of a centralised cross-departmental participatory network for consumers with disabilities.³²⁸

Article 11 requires that policies and programmes explicitly consider the particular needs of people with disabilities in their diversity and include

³²⁵ <http://www.dhsspsni.gov.uk/governance-controls>

³²⁶ <http://www.dhsspsni.gov.uk/governance-controls>

³²⁷ The Consumer Council (2011). Left high and dry: A Consumer Council report on consumers’ stories and experiences of the water crisis. Consumer Council: Belfast

³²⁸ E-mail correspondence from the Consumer Council 1st February 2011

measures which will ensure their protection and safety. Article 11 does not include an 'on an equal basis with others' clause and thus should be read as imposing obligations for the protection of persons with disabilities in situations of risk which do not necessarily exist for persons without disabilities.

Any purely utilitarian approach such as appears to be suggested in the HSC Guidance is incompatible with the rights-based approach of the UNCRPD. Human rights function as constraints on the extent to which policies and programmes may operate on a 'greatest benefit for the greatest number' calculation. This is observed in the prohibition of the torture of an individual even where there is considered to be great benefit for very large numbers of people. The obligation to take 'all necessary measures to ensure the protection and safety of persons with disabilities' requires that their needs be given special attention because without this they would inevitably be the losers in purely utilitarian calculations. However if the guidance in relation to planning for emergencies contained in the Northern Ireland Civil Contingencies Framework³²⁹ is implemented this incompatibility may be reduced.

5.7.4. Results from the questionnaire and focus groups

There were no direct results or comments from the focus group or the conference questionnaire. However the results in relation to access to information as previously reported in Article 9 are relevant and are reflective of those reported by the Consumer Council above.

5.8. Article 12: Equal recognition before the law

Article 12 - Equal recognition before the law

- 1 States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- 2 States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- 3 States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- 4 States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate

³²⁹ <http://www.ofmdfmi.gov.uk/ni-ccf-dec05.pdf>

and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

- 5 Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

With Article 12(1) States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

With Article 12(2) States Parties recognise that persons with disabilities enjoy legal capacity 'on an equal basis with others'. This explicitly applies in 'all aspects of life'. Article 12(2) thus requires the changing of any policy and the withdrawal or fundamental amendment of any programme which is premised on difference(s) between persons with disabilities and other persons as to legal capacity. This does not mean that there can be no recognition that people might possess different legal capacity (such as children under 16), nor that there cannot be policies or programmes tailored for people with different legal capacity (such as safeguards when decisions about medical treatment are being made for someone who is unconscious). It simply means that there can be no difference made as to legal capacity on the basis of disability as defined in Article 1 of the CRPD.

Any policy or programme based explicitly or implicitly on the premise that certain people (such as people with dementia, learning disability or mental health issues) necessarily lack the capacity to make decisions, or that in its practical outworking effectively treats someone as such, fails to meet the requirement of Article 12(2). As this Article explicitly applies to 'all areas of life', this exclusion is broad ranging and has implications across all areas where legal capacity is an issue without exception.³³⁰

³³⁰ See BMA Law Society guidance for illustration of range of situations

Article 12(3) requires States Parties to take 'appropriate measures' to provide access to the support persons with disabilities may require in exercising their legal capacity. It is not an obligation to so provide that support, but only to take measures to ensure access to that support. Such measures will obviously include enforceable policies within government departments and agencies to ensure that people are aware of their right to support and measures to ensure that there are programmes of support for the exercise of legal capacity which persons with disabilities can draw on.

Whilst the requirements of Article 12(3) may be seen as resource intensive, there is no reason to believe that the right to access the support needed to exercise one's legal capacity is a socio-economic right and thus is a progressively realisable obligation on States Parties as per CRPD Article 4(2). Recognition as a person before the law is an example of a classic civil and political right and it is of immediate effect. With respect to persons with disabilities, the obligation to take measures to ensure access to support under Article 12(3) is also of immediate effect. This means that Article 12(3) is not an obligation to provide access only through taking 'measures to the maximum of its available resources' (Article 4(2)). Article 12(3) support, must also not be seen as a form of 'reasonable accommodation' which is subject to limitation in 'not imposing a disproportionate or undue burden' (Article 2). The principle of the presumption of capacity for disabled people implicit in Articles 12(1) and 12(2) is akin to the principle of the presumption of innocence. Whilst there are reasonable limitations on the resources deployed to give effect to the presumption of innocence, no one is treated as guilty because it would be too 'costly' to treat them as innocent until otherwise proven.

A lack of resources cannot validly be used as an argument for the limitation of the legal capacity of persons with disabilities; nor can such a lack of validly be used as an argument for the limitation of their access to the support they may require in exercising their legal capacity.

Article 12 does not specify any particular forms of support for the exercise of legal capacity, nor what the 'appropriate measures' under Article 12(3) might be. Ultimately the Committee on the Rights of Persons with Disabilities will provide more substantive guidance on these issues, but in the meantime States Parties must take such measures to the best of its understanding. A lack of clarity around an obligation does not remove the obligation - it still falls to particular States Parties to give maximum effect to the obligation in their own context.

Article 12(4) refers to 'measures that relate to the exercise of legal capacity', but does not specify what precisely these are. They will vary between States Parties and between legal and political jurisdictions. Article 12(4) additionally imposes an obligation to have in place 'safeguards to prevent abuse' of

'measures which relate to the exercise of legal capacity'. Such 'safeguards' must meet explicit standards outlined within the article. That is, they must:

- respect the rights, will and preferences of the person;
- be free from conflicts of interest;
- be free from undue influence;
- be proportional;
- be tailored to the person's circumstances;
- should apply for the shortest time possible; and
- be subject to regular review by a competent, independent and impartial authority or judicial body.

In addition, there is a general requirement in Article 12(4) that any such safeguards to prevent abuse of measures that relate to the exercise of legal capacity shall be proportional to the degree to which those measures affect the person's rights and interests. All of the above applies to 'measures that relate to the exercise of legal capacity' which are in the nature of policies or programmes, including the requirement for safeguards to be built into such policies or programmes.

It is noteworthy that Article 12(4) does not apply to measures which relate to the exercise of legal capacity of persons with disabilities, but to measures which affect any person's legal capacity. This is clear when Article 12(4) is read in the light of Articles 12(1) and 12(2) which forbid distinctions with respect to legal capacity (and by implication to the safeguards required) on the basis of disability. The protection of the human rights of persons with disabilities is here to be achieved partly through the elimination of legal, policy or programmatic measures which distinguish on the basis of disability.

Article 12(5) contains the hard obligation to 'ensure that persons with disabilities are not arbitrarily deprived of their property'. Fulfilment of this obligation will require 'all appropriate and effective measures' be taken, including any appropriate policies and programmes to be in place.

Additionally, there is a general obligation to take 'all appropriate and effective measures' (which will include policies and programmes) to ensure an equal right for persons with disabilities to:

- own or inherit property;
- control their own financial affairs, and
- have equal access to bank loans, mortgages and other forms of financial credit.

5.8.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 12 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover, inter alia:

- Measures taken by the State Party to ensure that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life, in particular such measures as to ensure the equal right of persons with disabilities to maintain their physical and mental integrity, full participation as citizens, own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and their right not to be arbitrarily deprived of their property.
- The support available to persons with disabilities to exercise their legal capacity and manage their financial affairs.
- The existence of safeguards against abuse of supported decision-making models.
- Awareness-raising, and education campaigns in relation to equal recognition of all persons with disabilities before the law.

5.8.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

To date, State Reports to the Committee on Article 12 have focused on legal measures rather than policy or programmatic measures. The Reports have not proven useful in clarifying what States Parties consider the obligations of Article 12 to be with respect to policies and programmes.

5.8.3. Key policies and programmes in Northern Ireland relevant to Article 12

Article 12 is a highly significant Article in the Convention, sometimes even being referred to as the 'heart' of the CRPD. Many of the issues engaged by Article 12 are currently being addressed through the process of the reform of the Northern Ireland Mental Health Order and the development

of statutory Mental Capacity Law for Northern Ireland. The Northern Ireland Mental Capacity (Health, Welfare and Finance) Bill is currently under development and it will have a Code of Practice.³³¹ This Bill will require both a wide-ranging re-assessment of current policies and programmes for people who lack decision-making capacity, the development of new policies with respect to health, welfare and financial affairs and new programmes, such as a statutory advocacy service and training for appropriate health and social staff. DHSSPS have been running an extensive pre-consultation exercise on the requirements of the new law which has involved the development of around 20 confidential draft policy papers on various aspects of the new Bill. Due to the substantial and wide-ranging reforms currently underway in this area, we consider it unsuitable for detailed consideration as a key area.

5.8.4. Results from the questionnaire and focus groups

Mental health and capacity was the fourth highest priority for change for non disabled people in the questionnaire however the number of respondents was small (n=10). In the overall sample (disabled and non disabled people) it was rated as the sixth most important gap area between current policies and programmes and the requirements of the UNCRPD with 23 out of 27 respondents agreeing that mental health and capacity was a priority area.

It was noted however that there were very few comments from focus group participants or questionnaire respondents. This mismatch suggests that the priority given to this area in the quantitative question may be a reflection of the current intense debate currently taking place on mental health and capacity.

The comments received from the focus group participants and questionnaire respondents, related to a lack of awareness of mental disability and attitudes towards those disabled people.

“Knowledge deficit especially in relation to mental health within Government. There is a resource deficit”³³².

“The stigma associated with disability: people (especially those with power) are embarrassed by disability and want to deny its existence. The physical difficulties (travel etc) associated with participation, and the mental barriers- ‘Does he take sugar?’ The fact that many disabilities are mental ones- people with impaired cognitive functions may not be able to understand what is going on. I’m not sure what the answer is here- carers have to be part of the picture”³³³.

³³¹ Information about the Bill can be found in the EQIA consultation documents available on the DHSSPS website at <http://www.dhsspsni.gov.uk/showconsultations?txtid=43469>.

³³² Comment from the Representative Scoping Focus Group 14/1/2011.

³³³ Comment from a IMNI Conference questionnaire respondent.

5.9. Article 13: Access to Justice

Article 13 - Access to Justice

- 1 States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
- 2 In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 13(1) requires States Parties to ensure effective access to justice for persons with disabilities 'on an equal basis with others' in part through the provision of 'procedural and age-appropriate accommodations'. There must therefore be policies and programmes in place to both permit and require such accommodations as are appropriate to ensure access to justice for particular individuals. These accommodations are stated to apply to persons with disabilities as either direct or indirect participants, including as witnesses, in legal proceedings (including preliminary stages) and investigative stages. Article 13 is clearly intended to apply to both criminal and civil proceedings. 'Legal proceedings' should probably be interpreted widely to include quasi-judicial bodies such as tribunals making decisions when someone is detained under mental health laws or adjudicating on discrimination claims.

Article 13(2) recognises the importance of appropriate training for 'those working in the field of the administration of justice, including police and prison staff'. It imposes an obligation on State Parties to promote such training. This obligation can clearly only be fulfilled through at least a policy of requiring such 'appropriate training' on the part of relevant State agencies.

5.9.1. Consideration of other UN human rights treaties

The Human Rights Committee, in its General Comment on the administration of justice identifies a number of minimum guarantees in criminal proceedings. The following are of most relevance here with respect to potential policies and programmes. Firstly, the right of everyone to be informed of the charge against them in a language which they understand:

The right to be informed of the charge ‘promptly’ requires that information is given in a language they understand as soon as the charge is first made by a competent authority. Secondly, the accused must have adequate time and facilities for the preparation of their defence and to communicate with counsel of their own choosing. Thirdly, the accused shall be tried without undue delay. This guarantee relates not only to the time by which a trial should commence, but also the time by which it should end and judgement be rendered; all stages must take place “without undue delay”. Fourthly, if the accused cannot understand or speak the language used in court they are entitled to the assistance of an interpreter free of any charge.

The Committee on the Rights of the Child has stated that a child with a disability who comes in conflict with the law should be interviewed using appropriate languages and otherwise dealt with by professionals such as police officers, attorneys, advocates, social workers, prosecutors and/or judges, who have received proper training in this regard.³³⁴

5.9.2. Comments from the Committee on the rights of Persons with Disabilities

With respect to Article 13 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to ensure the effective access to justice at all stages of the legal process, including investigative and other preliminary stages, by all persons with disabilities;
- Measures taken to ensure effective training of personnel in the national justice and prison system, in the respect for the rights of persons with disabilities;
- The availability of reasonable accommodations, including procedural accommodations that are made in the legal process to ensure effective participation of all types of persons with disabilities in the justice system, whatever the role which they find themselves in (for example as victims, perpetrators, witness or member of jury, etc.);
- Age-related accommodations to ensure effective participation of children and young persons with disabilities.

5.9.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States

³³⁴ Committee on the Rights of the Child 43rd session (2006) at Para 74

Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

The State Report of **Australia** documents a number of measures that have been introduced to make courts more accessible to people with disabilities. These include making court facilities accessible, installing integrated hearing assistance systems, implementation of regular breaks where health reasons require it, offering a computer with screen reader or text-to-speech software or Braille display where required, and/or providing a signing interpreter. In addition, guidelines and training on disability has been made available to those who are involved in dealing with witnesses.³³⁵

To ensure access to justice of people with disabilities **Austria** has introduced a range of measures. For example; in certain circumstances experts are brought in to question a witness with disabilities; the legal information system offers information to ensure barrier-free access; provisions are in place to assist persons with sensory impairments with evidence; and an Ombudsman for Equal Treatment has been introduced to oversee the situation.³³⁶

The State Report from **China** states that in Hong Kong the Judicial Studies Board provides training programmes for judges and judicial officers at all levels of the court and runs conferences on the UNCRPD. Training is also offered to newly recruited and serving staff on the handling of prisoners with disabilities.³³⁷ To ensure that a person with disabilities' right to access to justice is vindicated the government of Macao have introduced measures to ensure that the courtrooms are physically accessible and interpreters are employed when required.³³⁸

It is compulsory in **Hungary** to offer sufficient assistance to people with disabilities in a courtroom environment. This includes providing a signing interpreter.

According to its report to the Committee, **Spain** has adopted a range of measures to ensure the right to access to justice is available to persons with disabilities. This includes ensuring the capacity to report offences and bring a

³³⁵ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 64-71.

³³⁶ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 21-22.

³³⁷ CRPD/C/CHN/1/Add.1, 'Report to the Committee on the Rights of Persons with Disabilities: Hong Kong' (30 August 2010), at para 13.1-13.15.

³³⁸ CRPD/C/CHN/1/ADD.2, 'Report to the Committee on the Rights of Persons with Disabilities: Macao' (30 August 2010), at para 42-43.

law suit, access to justice as a defendant, access to criminal proceedings as a witness and access to criminal proceedings as an expert. These requirements are provided for through legal aid, ensuring court rooms are physically accessible and offering interpreters or assistance where required.³³⁹

In order to facilitate legal recourse for persons with disabilities, **Tunisia** has taken measures to ensure their practical access to courts, as victims, suspects and witnesses, at all stages of legal proceedings, including by assigning sworn sign language interpreters to courtrooms.³⁴⁰

To ensure compliance with Article 13 and in order to ensure the correct application and interpretation of its principles, CERMI (the Article 33(2) body for Spain) considers it necessary to provide training and awareness-raising for Justice Administration professionals on the rights of persons with disabilities.³⁴¹

5.9.4. Key policies and programmes in Northern Ireland relevant to Article 12

A 2010 Leonard Cheshire report in England, 'Rights and Reality'³⁴², commented that only 1% of disabled people who have encountered discrimination when accessing goods and services have taken legal action to challenge it. In order to file a potential claim in Northern Ireland, a person must pay a fee of £150 - £180 (2010)³⁴³. Since disabled citizens often have lower incomes, this could be an issue. Although the fee can be waived in the case of financial hardship many people are unaware of this³⁴⁴ and if a complaint is made through the ECNI they may cover costs. In fact, a study by the Disability Rights Commission (DRC) indicated that the main reasons that disability claims are not made is the costs of the legal process and the stress of taking action³⁴⁵, as well as a lack of knowledge of disabled people's rights under the Act.³⁴⁶ The Equality Commission for Northern Ireland, which has

³³⁹ CRPD/C/ESP/1, 'Report to the Committee on the Rights of Persons with Disabilities: Spain' (3 May 2010), at para 70-74.

³⁴⁰ CRPD/C/TUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Tunisia' (14 July 2010), at para 101-103.

³⁴¹ CERMI, 'Human Rights and Disability: Spain Report 2009', 27 May 2010, 22.

³⁴² Leonard Cheshire Disability, (2010) Rights and reality; disabled peoples' experience of accessing goods and services.

³⁴³ <http://www.courtsni.gov.uk>.

³⁴⁴ Royal National Institute of Blind People (RNIB) (2009) referenced in Kuzma J.M (2009). Regulatory Compliance and Web Accessibility of UK Parliament Sites. Journal of Information, Law & Technology. (JILT).

³⁴⁵ Denvir, A, Broughton, A, Gifford, J and Hill, D (2007), Research Paper: The experiences of sexual orientation and religion or belief discrimination employment tribunal claimants, Department of Trade and Industry, [online] <<http://www.employment-studies.co.uk/pdflibrary/acas0207.pdf>>

³⁴⁶ Leonard Cheshire Disability, (2010) Rights and reality; disabled peoples' experience of accessing goods and services. Leonard Cheshire Disability:UK.

the powers of enforcement of the DDA and actively promotes compliance amongst service providers, reported that the general public's knowledge of the DDA has fallen from 83% in 2005 to 69% in 2008.³⁴⁷

Because of the difficulty with the process of bringing disabilities claims, the RNIB³⁴⁸ recommends that the government make changes to the claims process in order to overcome barriers in bringing cases to court, such as bringing cases in front of tribunals who are better trained in disability issues. This format was also recommended by the Leonard Cheshire Report in that they called for the establishment of a pilot project allowing formal arbitration of cases, so that they can be heard and settled before having to go to court, as well as the use of 'Equality Tribunals'. Consideration should also be given to introducing the capacity for joint or representative actions on accessibility issues and proactive enquiries such as undertaken by enforcement authorities on the selling of alcohol and cigarettes to minors.

5.9.4.1. Hate crime

Disability hate crime is defined by the PSNI as any incident that is perceived to be on the grounds of a person's physical or mental impairment by the victim or any other person. In Northern Ireland a research report was commissioned by the Office of the First Minister and Deputy First Minister, the Northern Ireland Office Community Safety Unit and the Police Service of Northern Ireland (PSNI). The Institute for Conflict Research (ICR) report titled: 'Hate Crime against People with Disabilities - A baseline study of experiences in Northern Ireland'³⁴⁹, was published in 2009 and made a number of recommendations for the police service, government and the voluntary/ community sector. In particular a recommendation was made that OFMDFM should be responsible for monitoring progress in responding to issues raised in the report and should convene a working group of partner agencies on a bi-annual basis to this end. Disability Action is not aware of any progress on the implementation of any recommendations from the report.

The NISALD survey 2006-2007³⁵⁰ reported that of the sample of 3543 disabled individuals interviewed, 8% of males and 5% of females with disabilities had experienced some form of hate crime. Furthermore experiences varied by the nature of the individual's disability, with 12% of people with a psychological disability reporting an experience of hate

³⁴⁷ ECNI (2008) Equality Awareness Survey. ECNI: Belfast.

³⁴⁸ Royal National Institute of Blind People (RNIB) (2009) referenced in Kuzma J.M (2009). Regulatory Compliance and Web Accessibility of UK Parliament Sites. Journal of Information, Law & Technology. (JILT).

³⁴⁹ Vincent F, Radford K, Jarman N, Martynowicz A & Rallings M-K, (2009). Hate Crime against People with Disabilities; A baseline study of experiences in Northern Ireland. Institute for Conflict Research: Belfast.

³⁵⁰ Ibid, Page 4

crime, compared to 6% of people with a sensory disability, a similar figure for people with a physical disability and 8% with people with 'other' forms of disability. However the numbers involved may be much higher as Mencap estimate that as many as 9 out of 10 people with a learning disability are verbally harassed or exposed to violence due to their disability³⁵¹ and Scope reported that a ComRes study of 533 disabled people in 2011 found that more than half of disabled people say they have experienced hostility, aggression or violence from a stranger because of their condition or impairment (56%). Half of disabled people in the ComRes study say they experience discrimination on either a daily or weekly basis and that more than a third (37%) said people's attitudes towards them have got worse over the past year³⁵².

These figures are not reflected in the PSNI statistics in relation to disability hate crime which showed in 2009/10 that there were only 58 incidents of disability hate crime reported³⁵³ – highlighting a potential under-reporting of incidences of hate crime. Forty one of these incidents were recorded as crimes and only 6 were cleared. It is not known how many were prosecuted.

In 2009 the Equality and Human Rights Commission in Great Britain started an inquiry in relation to disability harassment after a number of high profile cases in the media. Disability Action wrote to the Equality Commission and the Human Rights Commission in Northern Ireland to ask if a similar inquiry would be undertaken in Northern Ireland, the response was that no such inquiry would be undertaken.

Disability Action and other voluntary sector groups are actively campaigning to raise the awareness of hate crime and to bring main stakeholders together. A report completed for Mencap as part of its 3 year 'Stand By Me' campaign supported by the ECNI, was launched in June 2011. While highlighting "some examples of good police practice, it revealed a general lack of police understanding of disability hate crime. Many police officers don't understand what learning disability is, do not treat disability hate crime as a priority and do not record disability hate crime³⁵⁴.

5.9.4.2. Court witnesses

Current disability discrimination law places a duty on courts to treat disabled people fairly and to make reasonable adjustments under the DDA to ensure that they can take part in the Justice system on an equal basis with people without a disability. For example, if a court user has a visual impairment then

³⁵¹ <http://www.mencap.org.uk/news/article/it-s-learning-disability-week>.

³⁵² <http://www.scope.org.uk/news/attitudes-towards-disabled-people-survey>.

³⁵³ PSNI (2010). PSNI Annual Statistical Report No.3, Hate Incidents & Crimes, 1st April 2009 – 31 March 2010. PSNI: Belfast.

³⁵⁴ <http://www.mencap.org.uk/news/article/it-s-learning-disability-week>

the court should send out information in an accessible format. It also means that the State should give extra help to disabled people to enable them to participate in the court, as claimant, defendant, witness or appropriate adult. This support could be, for example, through 'intermediaries', legal aid or specialist services.

The new Justice Ministry has brought forward a series of measures which will assist people with disabilities. The new Justice Bill will improve the range of special measures for the giving of evidence by vulnerable and intimidated witnesses in court and will allow intermediaries to assist vulnerable defendants. It proposes to extend the Livelink (TV link) opportunities to allow patients subject to mental health detention in psychiatric hospitals to avail of live links where appropriate and to allow those with a physical disability to qualify for their use – currently the provisions are only available in respect of mental disorder. Further guidance in relation to contact with witnesses is at the consultation stage. All these measures are welcomed and the full participation of disabled people and their representatives is recommended to ensure the effectiveness of the proposals.

Stereotypes of disabled people as court witnesses remain problematic as highlighted by the Criminal Justice Inspectorate 2010 (see Article 16 post) thematic inspection on sexual violence and abuse³⁵⁵ which found that in cases where victims had learning difficulties or a physical disability and the issue of victim and perpetrator credibility was critical, it was unlikely that many of these cases would be directed for prosecution or result in a successful conviction. These difficulties may be only effectively tackled through awareness raising in the criminal justice system and the general public. Interestingly a court in Great Britain has recently concluded that if a witness with a mental health condition is not given appropriate support but instead treated as an unreliable witness because of stereotyping or false assumptions, then this may amount to breach of the right to be free from degrading treatment.³⁵⁶

5.9.5. Results from the questionnaire and focus groups

Focus groups participants reported that they had difficulty accessing justice due to negative attitudes prevalent in the courts including stereotypical views of people with learning difficulties as witnesses.

“The prejudice of the courts, jury etc to disabled people”³⁵⁷.

³⁵⁵ Criminal Justice Inspectorate (2010) Sexual Violence And Abuse: A thematic inspection of the handling of sexual violence and abuse cases by the Criminal Justice System in Northern Ireland. Criminal Justice Inspectorate: UK.

³⁵⁶ R (B) v Director of Public Prosecutions (Equality and Human Rights Commission intervening) [2009] EWHC 106 (Admin) [2009] WLR (D) 25 QBD.)

³⁵⁷ Comment by a NGO representative at the Scoping Focus Group on the 10/1/2011

“People with learning difficulties are not gaining access to justice due to staff (or institutional) attitudes in relation to their capacity as witnesses”³⁵⁸.

5.10. Article 14: Liberty and security of person

Article 14 - Liberty and security of the person

- 1 States Parties shall ensure that persons with disabilities, on an equal basis with others:
 - (a) Enjoy the right to liberty and security of person;
 - (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.
- 2 States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.

Article 14(1) mainly requires legal measures, but the important rule that ‘existence of a disability shall in **no case** justify a deprivation of liberty’ [emphasis added] cannot be effectively enforced by legal means alone. This is because it addresses the **justification** for a deprivation of liberty, rather than the **fact** of a deprivation of liberty. It thus requires that States Parties have appropriate policies and programmes in place within settings where a deprivation of liberty is a reasonable possibility, such as within the criminal justice system and within health and social care settings, including residential settings. Such policies and programmes should seek to ensure that persons with disabilities are not deprived of their liberty unlawfully, nor lawfully but ‘arbitrarily’. Programmes of education and training for anyone working with disabilities who may have the power to formally or informally deprive a person with a disability of their liberty are clearly a requirement of delivering on the substantive content of Article 14(1) (b).

Article 14(2) requires States Parties to ensure that should persons with disabilities be deprived of their liberty, they are treated on an equal basis

³⁵⁸ Comment by a NGO representative at the Third Thematic focus group on the 18/2/2011.

with respect to their human rights equivalent to that guaranteed to persons without a disability. Article 14(2) also includes the requirement for the provision of reasonable accommodation and that persons with disabilities are treated in compliance with 'the objectives and principles of the present Convention' - that is, in keeping with the 'object and purpose' of Article 1 and the 'principles' contained in Article 3.

The Human Rights Committee has highlighted that the right to liberty and security of persons is applicable to anyone deprived of liberty under the laws and authority of the State who is held in prisons, hospitals - particularly psychiatric hospitals - detention camps or correctional institutions or elsewhere.³⁵⁹ The right to liberty and security of person in the context of Article 10 ICCPR imposes on States Parties a positive obligation towards persons who are particularly vulnerable because of their status as persons deprived of liberty. The Committee requests specific information from States Parties concerning the measures taken to provide teaching, education and re-education, vocational guidance and training and also concerning work programmes for prisoners inside the penitentiary establishment as well as outside. The Committee also requests information on the specific measures applied during detention, e.g., how convicted persons are dealt with individually and how they are categorised, the disciplinary system, solitary confinement and high-security detention and the conditions under which contacts are ensured with the outside world (family, lawyer, social and medical services, non-governmental organisations).³⁶⁰

Deprivation of liberty must not be arbitrary, and must be based on grounds and procedures established by law, information of the reasons must be given, and court control of the detention must be available as well as compensation in the case of a breach.³⁶¹

With respect to Article 14 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken by the State Party to ensure that all persons with all forms of disabilities enjoy the right to liberty and security of person and that no person is deprived of her/his liberty on the basis of her/his disability;

³⁵⁹ Human Rights Committee (1992) General Comment 21: 'Humane treatment of persons deprived of liberty', at Para 1.

³⁶⁰ Human Rights Committee (1992) at Paras 12-13.

³⁶¹ Human Rights Committee (1982) General Comment 8: 'Right to liberty and security of person', at Para 4.

- Actions being taken to abolish any legislation that permits the institutionalisation or the deprivation of liberty of all persons with all forms of disabilities;
- Legislative and other measures put in place to ensure that persons with disabilities who have been deprived of their liberty are provided with the required reasonable accommodation, and benefit from the same procedural guarantees as all other persons to enjoy fully their remaining human rights.

5.10.1. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

The **Australian** report documents that a Disability Policy and Research Working Group has been set up with the role of creating a best practice framework in relation to restrictive practices. It aims to develop consistent definitions on restraints and their application, share information on best practice, identify barriers to reduce restrictive practices and identify positive behaviour support strategies. Senior Practitioners have been introduced to monitor, audit and investigate restrictive interventions against people with disabilities. With regard to the detention of persons with mental illnesses the 'National Mental Health Seclusion and Restraint Project' has been initiated with a view to eliminating the use of seclusion and restraint in public mental health services. The Seclusion and Restraint Working Party have been entrusted with developing national principles and procedures for the use of seclusion within broader guidelines relating to the management of disturbed/violent behaviour in inpatient psychiatric settings.

In dealing with the deprivation of liberty in the criminal justice context special training programs for prison staff have been developed, a dedicated Personal Support Unit is being trialled to accommodate offenders with impaired cognitive functioning and 'Primary Health Care Standards' have been introduced. Furthermore, an 'Intellectual Disability Diversion Program' is in operation in juvenile detention centres to divert offenders with intellectual disabilities who are charged with minor offences from court to community based interventions.³⁶²

³⁶² CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 72-84.

Tunisia has reported to the Committee that the Chairperson for the Higher Council for Human Rights and Fundamental Freedoms is authorised to conduct unannounced visits to penal and reform institutions, detention centres, children's shelters and institutions for persons with special needs in order to assess the compliance of those institutions with national legislation. Proposals to ensure the right of persons with disabilities to liberty and security of person is vindicated have included creating a representative committee to monitor all categories of disability. It has also included other measures such as, formulating a plan to sensitise the relevant parties to the need for action to ensure full implementation of rights; adding certain disabilities to the list of chronic illnesses that are fully covered; allowing tax and customs exemptions for machines and equipment intended solely for persons with disabilities; and establishing a programme for visits by the Higher Council to associations and foundations.³⁶³

In its shadow report on **Spain**, CERMI has advocated that each person diagnosed with a mental illness should be guaranteed appropriate integral treatment. Furthermore, the community mental health centre/unit should have a multidisciplinary team to ensure the necessary continuity of care, from the perspective of accessibility and adaptation of the needs of each person, home care and assertive treatment. CERMI argue this would prevent any possibility of involuntary clinic treatment and would avoid internment as a reactive measure for acute episodes.³⁶⁴

In its shadow report on Tunisia, The Atlas Council highlighted that increased efforts are required to ensure that policies and programmes reflect deinstitutionalisation.³⁶⁵

5.10.2. Key policies and programmes in Northern Ireland relevant to Article 14

Implementation of Article 14 is almost exclusively through legal measures, but there is a requirement that States Parties have appropriate policies and programmes in place within settings where a deprivation of liberty is a reasonable possibility, such as within the criminal justice system and within health and social care settings, including residential settings. Such policies and programmes should seek to ensure that persons with disabilities are not deprived of their liberty 'arbitrarily' even where it is lawful. Programmes of education and training for people who may have the power to formally or informally deprive a person with a disability of their liberty are clearly a requirement of delivering on the substantive content of Article (1)(b) and

³⁶³ CRPD/C/TUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Tunisia' (14 July 2010), at para 104-109.

³⁶⁴ CERMI, 'Human Rights and Disability: Spain Report 2009', 27 May 2010, at 24.

³⁶⁵ Atlas Council (2010), 'Redefining Disability', at 6.

such programmes do not generally exist. Where disability awareness training is provided, it is on an ad hoc basis and is not focused on the prevention of arbitrary deprivation of liberty. There is a clear gap in Northern Ireland in terms of safeguards in situations of deprivation of liberty that the Mental Capacity (Health, Welfare and Finance) Bill aims to address this situation.

The assessment of the adequacy of general policies and programmes within Northern Ireland with respect to Article 14 is complicated as Article 5 of the European Convention on Human Rights (ECHR) permits lawful detention on the grounds of 'unsound mind'. This may mean that policies and programmes are adequate in terms of the ECHR, but the ECHR is itself incompatible with the CRPD standard. Until the legal situation is clarified, it is not possible to assess the adequacy of policies and programmes which are implementing an incoherent standard within the international human rights system.

There were no specific results from either the conference questionnaire or the focus groups in relation to this article.

5.11. Article 15: Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment

- 1 No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation.
- 2 States Parties shall take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

This article reiterates the obligation contained in Article 3 of the European Convention on Human Rights and it engages a very wide range of policies and programmes, but not in a disability specific manner. There is a CRPD specific addition in the second sentence of Article 15(1) which stresses something of particular concern with respect to disabled people.

The second sentence of Article 15(1) contains a hard obligation which seems particularly broad ranging in its effect. At face value, this seems to rule out any medical or scientific experimentation being conducted on someone who

lacks the capacity to give free consent to their participation. This would require the withdrawal of any policy which permits such experimentation and halting of any medical or scientific research which involves the participation of people who have not themselves given free consent. Article 15(2) requires 'legislative, administrative, judicial or other measures' to be taken to prevent persons with disabilities from being subjected to torture or cruel, inhuman or degrading treatment. 'Other measures' includes having in place appropriate policies and programmes.

5.11.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 15 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to protect effectively persons with disabilities from medical or scientific experimentation without their free and informed consent, including persons with disabilities who need support in exercising their legal capacity;
- The inclusion of persons with disabilities in national strategies and mechanisms to prevent torture.

5.11.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

In Hong Kong, **China** has introduced a 'Code of Professional Conduct' which all Medical Practitioners must abide by to protect against medical or scientific experimentation without free and informed consent of persons with disabilities.³⁶⁶

Spain has laid down sanctions within the disciplinary rules of the National Police Corps and Civil Guards to protect persons, including persons with

³⁶⁶ CRPD/C/CHN/1/Add.1, 'Report to the Committee on the Rights of Persons with Disabilities: Hong Kong' (30 August 2010), at para 15.5-15.8.

disabilities, from torture or cruel, inhuman or degrading treatment or punishment.³⁶⁷

5.11.3. Key policies and programmes in Northern Ireland relevant to Article 15

Research involving disabled people that makes use of State resources or involves staff, patients or service users of the health and social services must be approved by an ethics committee. The policies and programmes are not disability specific in any way.³⁶⁸ Insofar as the potential research subjects lack capacity, there are legal, rather than solely policy, requirements which must be met.

There are a wide range of policies and programmes which address the requirements of this Article, but these are not specific to people with disabilities. Key programmes which implement Article 15 in Northern Ireland and are of most relevance to disabled people are in the work carried out by the Regulation and Quality Improvement Authority (RQIA).³⁶⁹ The RQIA registers and inspects a wide range of health and social care services, including nursing, residential care and children's homes to examine all aspects of the care provided, to assure the comfort and dignity of those using the facilities. It is also responsible for the regulation of day care settings, domiciliary care agencies, nursing agencies and a range of independent health care services. Under the Health and Social Care (Reform) Act (NI) 2009, RQIA undertakes a range of responsibilities for people with a mental illness and those with a learning disability. These include:

- preventing ill treatment;
- remedying any deficiency in care or treatment;
- terminating improper detention in a hospital or guardianship; and
- preventing or redressing loss or damage to a patient's property.

The relevance of the programmes of work carried out by the RQIA to implementing Article 15 is underlined by its role within the UK National Preventive Mechanism under the Optional Protocol to the UN Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT).³⁷⁰

There were no specific results from either the conference questionnaire or the focus groups in relation to this article.

³⁶⁷ CRPD/C/ESP/1, 'Report to the Committee on the Rights of Persons with Disabilities: Spain' (3 May 2010), at para 78.

³⁶⁸ See Office of Research Ethics Northern Ireland, Business Services Organisation. <http://www.hscbusiness.hscni.net/services/1852.htm>

³⁶⁹ <http://www.rqia.org.uk/home/index.cfm>

³⁷⁰ <http://www.justice.gov.uk/inspectorates/hmi-prisons/2536.htm>

5.12. Article 16: Freedom from exploitation, violence and abuse

Article 16 - Freedom from exploitation, violence and abuse

- 1 States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
- 2 States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognise and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
- 3 In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
- 4 States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
- 5 States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 16(1) requires that States Parties 'take all appropriate measures... to protect persons with disabilities from all forms of exploitation, violence and abuse'. The measures that States Parties are obliged to take clearly

include policies and programmes such as:

- legislative;
- administrative;
- social;
- educational; and
- other measures.

The measures should cover both 'within and outside the home' and should include the 'gender based' aspects of exploitation, violence and abuse. 'Within and outside the home' is a significant phrase as it indicates that States Parties should take measures to protect persons with disabilities from exploitation, violence and abuse not just from the State, but also from private entities, including family members. Explicit attention must be given in measures taken to the gender-based causes of such exploitation, violence and abuse.

Article 16(1) sets no limits on its scope in terms of where it applies and thus it creates an obligation for States Parties to have measures in place to address exploitation, violence and abuse in all areas of society and social interaction, including the private sphere as well as the public sphere.

Whilst Article 16(1) requires measures to **protect** from 'all forms of exploitation, violence and abuse', Article 16(2) requires States Parties to take 'all appropriate measures' to **prevent** the same. Article 16(2) proceeds to elaborate what, amongst other things, must be done by States Parties to ensure the prevention of 'all forms of exploitation, violence and abuse' of persons with disabilities. States Parties must ensure appropriate forms of gender- and age-sensitive assistance and support for: (1) persons with disabilities; (2) their families; and (3) caregivers. This must include the provision of information and education on how to avoid, recognise and report instances of exploitation, violence and abuse. In addition, States Parties must ensure that protection services are age-, gender- and disability-sensitive.

With respect to Article 16 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State Report should cover:

- Administrative, social, educational and other measures taken to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including the gender and child based aspects.
- Social protection measures to assist and support persons with disabilities, including their families and caregivers, and to prevent,

recognise and report instances of exploitation, violence and abuse, including the gender- and child-based aspects.

- Measures taken to ensure that all services and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
- Measures taken to ensure that all persons with disabilities who are victims of violence have access to effective recovery, rehabilitation and social re-integration services and programmes.
- Measures taken to ensure that all services and resources available to prevent and support victims of violence are accessible to persons with disabilities.
- Policies, including women and child focused policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

5.12.1. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

A number of measures have been introduced in **Australia** to ensure freedom from exploitation, violence and abuse for everyone, including persons with disabilities. In order to reduce violence against women and their children a 'Respectful Relationships' program and 'Women with Disabilities Australia' group have been set up. A National Disability Abuse and Neglect Hotline has come into operation. Furthermore, a variety of roles have been created to protect such persons including a Disability Services Commissioner, an Adult Guardian and a Health and Community Services Complaint Commissioner in various parts of Australia. Government agencies have been assigned responsibility for investigating allegations and an 'objective fault test' has been introduced in relation to sexual assault.³⁷¹

The Women's Affairs Department of the Federal Chancellery (BKA) of **Austria** provides funding for NGOs which advise, inform and support female victims

³⁷¹ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 87-94.

of violence with learning difficulties or multiple disabilities and their reference persons. Through this a number of brochures have been published and distributed in a number of formats and the Vienna Deaf and Mute Welfare Association has been developed. Furthermore, Protection against Violence Centres or an Intervention Agency has been introduced in every province as a social measure to accompany the Protection against Violence Act.³⁷²

China has reported that the Hong Kong government's strategy concerning Article 16 of the UNCRPD is to provide a continuum of preventative, supportive and specialised services at the primary, secondary and tertiary levels. Preventative services have included enhancing public awareness on the prevention of domestic violence and the importance of family solidarity, and to encourage victims to seek early assistance through public education, publicity campaigns and outreaching programmes. Supportive services have been introduced to provide information, resources and support to needy families, and to provide residential care for children in need. Within this a Victim Support Programme and Compassionate Rehousing Scheme have been set up. Specialised services offered include providing crisis intervention services for battered women and their dependent children, through refuge centres, family crisis support centre and specialised units. Furthermore, a multi-disciplinary approach is used in Hong Kong to tackle the problem of domestic violence. The Committee on Child Abuse and the Working Group on Combating Violence oversee this aspect. Measures introduced using this approach include setting up District Co-ordinating Committees on Family and Child Welfare and District Liaison Groups on Family Violence, collaborating with NGOs to provide training and carry out research, drafting procedural guidelines for handling abuse cases, and setting up a referral mechanism designed to expedite professional intervention in cases of domestic violence for the police. The police have established a 24 hour direct referral telephone line and have introduced a staged system where urgent and high-risk cases are dealt with promptly.³⁷³ However, it is not clear that these measures have an explicit disability focus.

In **Spain** Part V of the Third Plan for Persons with Disabilities 2009-2012 provides for a number of measures designed to prevent abuses and acts of violence committed against persons with disabilities, particularly minors and women, and to facilitate their detection. The measures include investigations, awareness-raising campaigns, manuals for professional workers, and other training activities.³⁷⁴

³⁷² CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 24.

³⁷³ CRPD/C/CHN/1/Add.1, 'Report to the Committee on the Rights of Persons with Disabilities: Hong Kong' (30 August 2010), at para 16.1-16.8.

³⁷⁴ CRPD/C/ESP/1, 'Report to the Committee on the Rights of Persons with Disabilities: Spain' (3 May 2010), at para 79-87

Tunisia has taken a number of measures designed to help persons with disabilities maintain their health and ensure their access to rehabilitation, education and training for integration into the life of society. The Higher Council for Human Rights and Fundamental Freedoms conducts visits to institutions that care for persons with special needs in order to investigate and report cases of exploitation, violence and abuse. Additionally, institutions of higher learning are charged with the task of monitoring education, rehabilitation and training programmes for persons with disabilities at accredited education centres, with a view to ensuring that they observe pedagogical practices suitable for children with disabilities and do not in any way put them at risk of exploitation, violence or abuse.³⁷⁵

5.12.2. Key policies and programmes in Northern Ireland relevant to Article 16

5.12.2.1. Sexual violence

Two key strategies tackling violence at home (October 2005) and sexual violence and abuse (June 2008)³⁷⁶ have been published and will run until June 2013. While both strategies include key actions in relation to supporting services for people from an ethnic minority background and / or from the LGB community there is none for disabled people.

The Criminal Justice Inspectorate 2010 thematic inspection on sexual violence and abuse commented that interviewees reported limited experience of cases involving victims who had learning difficulties or a physical disability.³⁷⁷ It further commented that a large proportion of sexual violence and abuse cases centre on the victim's word against the perpetrator's (for example, 71% of non-prosecuted cases and 50% of prosecuted cases in the case file review). The Criminal Justice Inspectorate was advised by stakeholders that in such circumstances, the issue of victim and perpetrator credibility became more critical and therefore it was unlikely that many of these cases would be directed for prosecution or result in a successful conviction. The issue of vulnerable adults in the criminal justice system generally was a concern for some interviewees but hopefully the development of the protocol for investigations involving vulnerable adults will improve this.

³⁷⁵ CRPD/C/TUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Tunisia' (14 July 2010), at para 113-114.

³⁷⁶ Draft Equality Plan for the Department of Health, Social Services and Public Safety p40, v1 January 2011.

³⁷⁷ Criminal Justice Inspectorate (2010) Sexual Violence And Abuse: A Thematic Inspection Of The Handling Of Sexual Violence And Abuse Cases By The Criminal Justice System In Northern Ireland, Criminal Justice Inspectorate

5.12.2.2. Human trafficking

Responsibility for issues of human trafficking, insofar as they are devolved, lies with the Department of Justice which recently launched a campaign to raise awareness of human trafficking.³⁷⁸ There is a lack of consideration of disability as an issue in connection with human trafficking.³⁷⁹ However, through its advocacy work, the Centre on Human Rights for Disabled People at Disability Action has encountered situations where it is likely that individual disabled people had been trafficked for economic and sexual exploitation. The absence of any specific policies or programmes which explicitly address disability as a feature of trafficking (in prevention measures or services for victims/suspected victims) is likely to be a gap in implementing Article 16 in Northern Ireland.

5.12.3. Results from the questionnaire and the focus groups

There were no specific results from either the questionnaire or the focus groups in relation to this article. However general comments were received which are contained in the section in Article 13 on Access to Justice.

5.13. Article 17: Protecting the integrity of the person

Article 17 - Protecting the integrity of the person

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

Article 17 is short and to the point in its obligation, but it obviously requires a range of specific policies and programmes to ensure its realisation in practice. The end stated in such a strong and clear fashion, clearly implies the means necessary for achieving that end. Particular regard would have to be given by States Parties to policies and programmes to ensure respect for the integrity of persons with disabilities in settings where their integrity is particularly

³⁷⁸ http://www.dojni.gov.uk/ford_launches_campaign_to_raise_awareness_of_human_trafficking.

³⁷⁹ For example see the relevant sections of: Department of Justice (2011). Research paper investigating the issues for women in Northern Ireland involved in prostitution and exploring best practice elsewhere" Department of Justice: Belfast [http://www.dojni.gov.uk/index/publications/final_research_paper_-_women_in_northern_ireland_involved_in_prostitution.pdf]; the Anti Trafficking Monitoring Group (ATMG) Report (2010) "Wrong Kind of Victim? One year on.... an analysis of UK measures to protect trafficked persons" (June, 2010) [http://www.amnesty.org.uk/uploads/documents/doc_21111.pdf]; and NIHRC/ECNI ".

at risk, for example, when a person's liberty is restricted to some degree or ability to defend his/her own physical and/or mental integrity is limited to some degree.

The policies and programmes it requires are clearly closely related to those required under Articles 15 and 16 and policies and programmes might be effectively developed and implemented to meet the obligations of the three articles in conjunction.

5.13.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 17 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to protect persons with disabilities from medical (or other) treatment given without the free and informed consent of the person.
- Measures taken to protect all persons with disabilities from forced sterilisation, and girls and women from forced abortions.
- The existence, composition and role of independent review organisations to ensure the fulfilment of this right, as well as the programmes and measures adopted by these bodies.

5.13.2. Reports to the Committee on the Rights Of Persons With Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

In **Austria** the protection of people with disabilities from medical and scientific experiments is guaranteed via the involvement of people with disabilities in various ethics commissions.³⁸⁰

³⁸⁰ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 25.

5.13.3. Key policies and programmes in Northern Ireland relevant to Article 17

Policies and programmes which aim at least in part to protect the integrity of persons are obviously very large in number. Protection of 'integrity' has been defined by the European Court of Human Rights in its case law on Article 8 of the European Convention on Human Rights as including 'physical, mental and moral' integrity. Respect for integrity is often seen as including treatment which does not reach the 'torture, inhuman or degrading treatment' threshold, yet is clearly a significant interference with a person of a broadly similar nature. It includes respect for the capacity to give, withhold or withdraw consent for health and social care interventions.

In terms of Northern Ireland policies and programmes, Article 17 overlaps considerably with Articles 15, and 16 as key relevant policies and programmes with respect to those articles would also be expected to protect individuals from interference with their integrity. No policies or programmes which seek to implement Article 17 specifically have been identified, but it is not clear, given the content of the other articles of the CRPD, that such policies and programmes are necessary.

5.13.4. Results from the questionnaire and the focus groups

There were no specific results from either the conference questionnaire or the focus groups in relation to this article.

5.14. Article 18: Liberty of movement and nationality

Article 18 - Liberty of movement and nationality

- 1 States Parties shall recognise the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others, including by ensuring that persons with disabilities:
 - (a) Have the right to acquire and change a nationality and are not deprived of their nationality arbitrarily or on the basis of disability;
 - (b) Are not deprived, on the basis of disability, of their ability to obtain, possess and utilise documentation of their nationality or other documentation of identification, or to utilise relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement;

- (c) Are free to leave any country, including their own;
 - (d) Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country.
2. Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

Article 18 (1) focuses mainly on ensuring that persons with disabilities are treated 'on an equal basis with others' when it comes to the area of liberty of movement and nationality, explicitly including 'immigration proceedings'. Freedom of choice of residence and to a nationality, must be assured to persons with disabilities 'on an equal basis with others' and thus any policy or programme which in principle permits or in fact allows persons with disabilities to be treated differently to others fails to meet the obligations of Article 18.

The general obligation clearly requires the withdrawal of any policy which seeks to use 'disability' as a potentially determining criterion for the differential treatment of individuals with respect to any decision about:

- nationality or immigration status;
- possession or use of documentation of nationality; or
- any other means 'that may be needed to facilitate exercise of the right to liberty of movement.

Article 18 (2) deals specifically with children with disabilities and requires that there be policies and programmes which ensure that they:

- be registered immediately after birth;
- shall have the right to a name; and
- shall have the right to acquire a nationality.

In addition, Article 18 (2) obliges States Parties that children with disabilities shall have, 'as far as possible', the right 'to know and be cared for by their parents'. The meaning of 'as far as possible' will only be determinable in particular cases, but the obligation clearly entails a 'proportionality' based approach in which the presumption is that the child will know and be cared for by their parents.

Article 18 (2) can also reasonably be read in conjunction with Article 5 on equality and non-discrimination as only permitting such exceptions as are

permitted to the right of non-disabled children 'to know and be cared for by their parents'. This obligation is wide ranging in its effect. It requires:

- the withdrawal of any policy which permits children with disabilities to be removed from their parents on the basis of the child's disability;
- programmes of family support sufficient to ensure that children with disabilities have as much opportunity as other children to know and be cared for by their parents.

5.14.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 18 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Administrative measures taken to ensure the right of persons with disabilities to acquire a nationality and to not be deprived of it, as well as to ensure the right of persons with disabilities to enter or leave the country arbitrarily;
- Measures taken to ensure that every newborn child with a disability be registered upon birth and given a name and a nationality.

5.14.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

Australia provides a number of services to ensure persons with disabilities are afforded the same de jure access to immigration proceedings as all other persons. Persons who have a hearing, speech or communication impairment can contact the Australian Department of Immigration and Citizenship through the National Relay Service, which provides electronic communication services for persons with hearing or speech impediments. The Translating and Interpreting Service may be used by visually impaired persons who are not sufficiently proficient in English. If clients have difficulty in accessing services by phone or through written communications, they are able to use third parties or agents to act on their behalf. In addition, the Migration Review Tribunal and Refugee Review Tribunal have a Disability Action Plan

which commits the Tribunals to ensuring that persons with disabilities are not disadvantaged when accessing their services.³⁸¹

5.14.3. Key policies and programmes in Northern Ireland relevant to Article 18

Article 18 focuses mainly on ensuring that persons with disabilities are treated 'on an equal basis with others' when it comes to the area of liberty of movement and nationality, explicitly including 'immigration proceedings'. The UK has placed a reservation on this matter stating 'The United Kingdom reserves the right to apply such legislation, insofar as it relates to the entry into, stay in and departure from the United Kingdom of those who do not have the right under the law of the United Kingdom to enter and remain in the United Kingdom, as it may deem necessary from time to time.'³⁸²

The matter is also an excepted matter under Schedule 2 to the Northern Ireland Act 1998 and is outside the remit of the Northern Ireland government.³⁸³ It is therefore considered outside the remit of the current study.

Enquiries have not revealed any areas of concern under the remaining sections of the Article which require the registration, naming and the nationality of disabled children.

Article 18 (2) can also reasonably be read in conjunction with Article 5 on equality and non-discrimination as only permitting such exceptions as are permitted to the right of non-disabled children 'to know and be cared for by their parents'. This obligation is wide ranging in its effect. It requires:

- The withdrawal of any policy which permits children with disabilities to be removed from their parents on the basis of the child's disability;
- Programmes of family support sufficient to ensure that children with disabilities have as much opportunity as other children to know and be cared for by their parents.

The policies in relation to programmes of family support sufficient to ensure that children with disabilities have as much opportunity as other children to know and be cared for by their parents is covered by the policy contained in Care Matters in Northern Ireland: A bridge to a better future (2007)³⁸⁴ and Families Matter: Supporting Families in Northern Ireland, Regional Family and Parenting Strategy, March 2009³⁸⁵. No areas of major concern have been raised.

³⁸¹ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 108-109.

³⁸² <http://www.un.org/disabilities/default.asp?id=475>.

³⁸³ <http://www.cabinetoffice.gov.uk/content/northern-ireland-what-devolved>.

³⁸⁴ <http://www.dhsspsni.gov.uk/care-matters-ni-3.pdf>

³⁸⁵ http://www.nidirect.gov.uk/families_matter_strategy.pdf

5.14.4. Results from the questionnaire and the focus groups

There were no specific results from either the conference questionnaire or the focus groups in relation to this Article.

5.15. Article 19: Independent living

Article 19 - Living independently and being included in the community

States Parties to this Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

With Article 19 States Parties recognise the equal right of all persons with disabilities to live in the community. It is important to note that the Article explicitly states 'all persons with disabilities' without qualification of any kind. In living in the community, persons with disabilities should have 'choices equal to others' - this provides a standard by which both the nature and the extent of policies and programmes which are required can be determined for any given State Party.

State Parties are obliged to take 'effective and appropriate measures' (which will include a range of policies and programmes) to 'facilitate' (not 'ensure') full enjoyment of this right. Distinct from the facilitation of enjoyment of

this right, there is also an obligation on States Parties to facilitate 'their full inclusion and participation in the community'. What is required of States Parties in fulfilment of this right and the nature of the obligation of 'full inclusion' is elaborated upon further in a non-exhaustive list of things which States Parties must 'ensure'. This list provides a check list against which policies and programmes can be measured as sufficient for the fulfilment of the obligations of this right. States Parties must ensure that persons with disabilities:

- Have the opportunity to choose their place of residence;
- Have the opportunity to choose where and with whom they live (on an equal basis with others);
- Are not obliged to live in a particular living arrangement; and
- Have access to a range of in-home, residential and community support services.

In a clear 'end implies the means' explicating phrase, Article 19 (b) stresses that support services must include 'personal assistance necessary to support living in the community and inclusion, and to prevent isolation or segregation from the community'.

Article 19 (c) requires that community services and facilities aimed at the general population be available to persons with disabilities 'on an equal basis' and that they be 'responsive to their needs'. This clearly requires policies and programmes across the range of community services and facilities to ensure that they are so available.

5.15.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 19 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- The existence of available independent living schemes, including the provision of personal assistants for persons who so require;
- The existence of in-house support services allowing persons with disabilities to live in their community;
- The existence and range of options of residential services for living arrangements, including shared and sheltered accommodation which take into account the form of disability;
- The degree of accessibility for persons with disabilities to community services and facilities provided to the general population.

5.15.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular article might be met.

In its State Report, **Australia** outlines that support for independent living is provided for by the 'Home and Community Care Program' and the 'Younger Persons with Disabilities in Residential Care Program'. The 'Home and Community Care Program' provides services such as domestic assistance, personal care and professional allied health care and nursing services. The 'Younger Persons with Disabilities in Residential Aged Care Program' aims to reduce the number of younger persons with disabilities living in, or at risk of admission to residential aged care throughout Australia and to provide enhanced disability support services for those who choose to remain in residential aged care, or for whom residential aged care is the only available suitable accommodation option. Community Living Initiatives have been set up for persons with disabilities. These ensure that the persons with disabilities and their family lead the decision-making for the planning and development of personalised supports that enable persons with disabilities to live in their own homes in the community.

The Australian government has dedicated funding to the States and Territories to manage and deliver public housing which is accessible for persons with disabilities. Allocation of funding for this purpose is overseen by the Disability Services Commission. Furthermore, moves are being made to introduce a universal design which encourages the development of well-located, accessible and affordable housing.

In New South Wales persons with disabilities who have ageing-related support needs are supported in their homes where possible, and are only referred to an aged care service if an Aged Care and Assessment Team indicated this need, and only then with client or guardian consent. The provision of housing that will increase the supply and diversity of residences that meet the needs of seniors or persons with a disability is encouraged. 'Individual Support Packages' for people with a disability to remain living in the community and funded services linking accommodation support and respite services have been made available. Furthermore, the 'National Disability Agreement' sets out older carers as a priority group and recognises carer age as a risk factor in determining priority of services.

Programs for persons with mental illnesses have been developed in Australia. 'The Fourth National Mental Health Plan, an Agenda for a Collaborative Government Action' provides a framework for developing a mental health system for early intervention. To support recovery and to prevent poor outcomes for people with mental illness, a range of bed-based clinical services, accommodation and housing service options are required. This includes more short-term and long-term clinically supported mental health accommodation services in the community and stable housing tenancy support for people with a disability as a result of their mental illness. For example, the 'Targeted Community Care (Mental Health) Program' provides community-based mental health service to support individuals on their recovery journey by improving life skills and quality of life, building resilience of families through increased skills and knowledge and supporting carers to maintain their caring roles.³⁸⁶

In **Austria** the current government programme includes plans –depending on the available financing - to provide federal funding for the further extension of social services. Possible measures include the extension of mobile services at weekends, semi-inpatient services, short-term care in homes, case and care management, and alternative forms of accommodation. Programmes currently in place include providing tax exemptions on non-profit making facilities and providing assistance in the workplace.³⁸⁷

Basic services enlisted in **Hungary's** Social Act are aimed at giving assistance, through the means of social work, to those in need of maintaining their life style as well as in solving their problems resulting from such matters as their health condition or mental state. Special basic services have several forms that back the independent living of persons with disabilities, their remaining with their families or their living in an own housing environment. The support service is aimed at transporting and providing personal assistance in performing activities at home for persons with physical disabilities, persons with sight or hearing impairment or for persons with mental disabilities or multiple disabilities. The goal of communal care is supporting psychiatric patients and their families. Daytime care is provided by daytime institutions, the home assistance service (fulfilment of basic caring and nursing duties, assistance in the prevention and elimination of emergencies) and by the home assistance service under the alarm system (assistance provided to persons with disabilities and psychiatric patients capable of using the alarm equipment for the elimination of crisis situations). If 24-hour care is needed for supporting independent living the traditional forms of institutional social care - caring - nursing homes, rehabilitation institutions provide solution

³⁸⁶ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 108-109.110-126.

³⁸⁷ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 26-29.

in addition to the homes operated for such persons. Beyond institutional rehabilitation care the so-called exterior accommodation is a new service form.³⁸⁸

In its shadow report on **Spain**, CERMI submits that the right to be included in the community under Article 19 of the UNCRPD requires the adaptation of all services, facilities and support resources so they are accessible for all persons with disabilities on an equal basis to others. Rural development plans should cover the perspective of disability paying particular attention to women and children with disabilities. In addition, CERMI call for new guidelines to be created which reflect the obligations and principles set out in the UNCRPD.³⁸⁹

5.15.3. Key policies and programmes in Northern Ireland relevant to Article 19

This is a complex area with a number of factors including housing and living arrangements, participation, personal mobility, access to information, support services and access to social and community services on an equal basis to others and the responsiveness and effectiveness of these services and policies. The right to advocacy under Article 12 for which there is no national strategy is also relevant. The area spans the remit of several Departments.

The significance of this area for the lives of people with disability was highlighted by a 2010 ONS survey in Great Britain³⁹⁰ which found that independent living is fundamental to achieving disability equality, enabling people with disabilities to fulfil the roles and responsibilities of citizenship; Twenty three per cent of persons with disabilities in the survey believed that they do not frequently have choice and control over their lives. The Parliamentary Joint Committee on Human Rights is holding an Inquiry from May 2011 into the implementation of the right of disabled people to independent living in the UK.³⁹¹

The 2009 PSI Report³⁹² regarded independent living as a goal through which every disabled person should be supported to empower themselves to become active, independent citizens with the freedom to make choices that affect their lives and avail of services that are individual centered and accessible. The PSI Report recommended that the “the Northern Ireland Executive should undertake a review of “Independent Living” and place

³⁸⁸ CRPD/C/HUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Hungary' (14 October 2010), at para 108.8.

³⁸⁹ CERMI, 'Human Rights and Disability: Spain Report 2009', 27 May 2010, at 26.

³⁹⁰ ONS (2010) Opinion Survey

³⁹¹ <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/right-of-disabled-people-to-independent-living-call-for-evidence/>

³⁹² OFMdFM (2009) Annex to the report of the Promoting Social Inclusion working group on Disability

Independent Living at the centre of its focus on Disability Issues. The review should identify practical and innovative ways to enable disabled people to live their lives the way they want to"³⁹³. To date, no review has been released although it was noted that the OFMdfM Disability Unit held a meeting to establish progress on the PSI Report's recommendations in January 2011.

5.15.3.1. Direct payments

In Northern Ireland, independent living is currently intended to be facilitated through Social Care legislation such as the Personal Social Services and Children's Services (Direct Payments) Regulations (Northern Ireland) 2004, the Chronically Sick and Disabled Persons Northern Ireland Act 1978, the Health and Personal Social Services (Northern Ireland) Order 1972 and principally in the Carers and Direct Payments Act (Northern Ireland) 2002 (CDPA). This statutory scheme provides for the authority to provide funds to the patient to contract with others to buy in services or benefits to help them cope with their disabilities. Section 8 of the CDPA 2002 Act envisages a contract between the patient and the authority.

Approximately 1,800 people are on this scheme however when this is compared to the approximately 183,000 receiving Disability Living Allowance (DLA) and 53,000 receiving Carer's allowance it is clear that Direct Payments are a very small element of community social care.

The judgment in the judicial review, PF and JF v the Southern Eastern Health and Social Care Trust (2011)³⁹⁴ has highlighted a legislative gap in Northern Ireland with regard to the consent requirement in Section 8 of the CDPA 2002 Act which is required to lay a proper legal basis for a direct payments scheme entered into directly with a carer in the case of a person under mental disability.

In England, the Health and Social Care Act 2008 Section 146 and the Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2009 effectively avoided the problem to be found in Section 8 of the Northern Ireland Act. The English legislation amended Section 57 of the English 2002 Act (the equivalent provision of Section 8) to permit payment to a suitable representative of a patient with disability which has deprived the disabled person with the power to consent. The judicial review judgement commented (paragraph 37) that it was 'somewhat surprising that the Department in this jurisdiction was apparently unaware of the English amendment or the need to amend Section 8 to lay a proper legal basis for a direct payments scheme entered into directly with a carer in the case of a person with a mental disability'.

³⁹³ Annex to the report of the Promoting Social Inclusion working group on Disability, Recommendation 48, 2009 Disability

³⁹⁴ PF and JF's Application (2011) NIQB 20, Judgement delivered 7/3/11

This judgement will affect a number of people currently on direct payment. Action should be taken by the authorities in Northern Ireland to apply for a controller to be appointed on their behalf under Article 101(1) of the Mental Health (Northern Ireland) Order 1986 where applicable or pass the necessary legislative amendment.

5.15.3.2. Self directed support

Another type of independent living strategy currently available in GB but for which there is no National Strategy in Northern Ireland is the personalisation of services or 'Self Directed Support'. The idea behind Self Directed Support is to give people real choice and control over the support they receive, as opposed to other people deciding for them. People can choose to be involved in planning and organising their own support, or they can choose others to do it for them.

The process goes through seven stages and it involves the training of the disabled individual, support workers and any suppliers of the services. Further details can be obtained from the In Control website.³⁹⁵ This system (Self Directed Support) would appear to be in greater compliance with the UNCRPD than the system of direct payments as it increases the choice and control for the individual. The payments can be used to pay for anything, including a football season ticket provided that it meets the agreed aims drawn up at the start of the process.

While there is no policy in Northern Ireland for the system, a small scale project (30 people) is starting (April 2011) independently in the Southern Trust. This project is entirely within the control of the Southern Trust and if successful will be promoted to the other Trusts.³⁹⁶ Within this system it is expected that choice will be maintained even in reduced resourcing. The scheme will however be subject to the legislative problems above (see 5.15.2.1) if the person with the disability is unable to consent or the necessary legal structures are not put in place.

Northern Ireland lags behind the rest of the UK in the speed of change from institutional care to independent living. An Audit Office report on the 'Resettlement of long-stay patients from learning disability hospitals' found that in March 2009, 256 patients remained in long-stay hospitals in Northern Ireland despite the Department setting a target in 1997 that all patients in long-stay learning disability hospitals would be resettled by 2002. This target has been revised repeatedly and is now set for 2013. This process is the subject of a current High Court review in Belfast to challenge the delayed discharge of patients from Muckamore Abbey Hospital.

³⁹⁵ <http://www.in-control.org.uk/resources/fact-sheets.aspx>

³⁹⁶ Information from Project Lead for Self Directed Support Southern Health & Social Care Trust Self Directed Support Project, December 2010.

5.15.3.3. The Supporting People (SP) programme

The Supporting People (SP) programme managed by the Northern Ireland Housing Executive works in partnership with the Health and Social Care Board, the five Health and Social Care Trusts and the Probation Board for Northern Ireland and provides a range of services, including advice and guidance, to enable disabled people and others with support needs to live as independently as possible. The four (soon to be five) Area Supporting People Partnerships (ASSPs) are also central to the commissioning process in terms of assessing and prioritising the housing support needs of vulnerable client groups at local level.³⁹⁷ This programme helps deliver the Northern Ireland Supporting People Strategies 2005-10 and the PSI Homelessness Strategy 2010-15.

A 2010 review³⁹⁸ of the supporting people programmes across the UK revealed that there is a lack of robust, peer-reviewed research evidence which explores the impact in terms of outcomes for service users as well as the effectiveness of different types of programme administration/funding in terms of the ability of service providers to meet the housing-related needs of vulnerable adults. The evidence available predominantly highlights the positive impacts of SP for service users in terms of outcomes such as independent living and quality of life. However, such outcomes have not been measured using robust research methods and there is a lack of evidence from service users themselves. None of the literature reports any adverse outcomes for service users although the review does reveal some concerns that the that services do not adequately address the needs of different groups (e.g. ethnic minority groups). In view of the evidence on access to information and the potentially lower uptake of services for certain types of disability contained in Article 9, further research is recommend on the impact of the SP programmes for disabled people.

5.15.3.4. Funding

While not within the remit of this study it is clear that funding restrictions due to the UK economy will enviably result on the State's ability to fully implement the UNCRPD. In some instances this may lead to a regression of rights already enjoyed. The IMNI commented on this in their submission to the Joint Committee inquiry into independent living³⁹⁹ when they reported on the reforms to the Disability Living Allowance, **"In particular, the Committee should note the ongoing challenges faced by Northern Ireland, related to the past conflict and high levels of poverty, with**

³⁹⁷ http://www.nihe.gov.uk/index/wwu_home/supporting_people-3.htm

³⁹⁸ www2.nphs.wales.nhs.uk:8080/.../LB_supporting%20people%20review%20_FINAL_QA.doc.

³⁹⁹ IMNI (2011) Evidence to the Joint Committee on Human Rights

proportionally more people in receipt of DLA benefit in Northern Ireland than elsewhere in the United Kingdom. The Department for Social Development estimates that over 184,500 people in Northern Ireland receive DLA. The proportion of working age people in receipt of DLA in Northern Ireland is approximately twice the level in Great Britain - 10.3 per cent of the Northern Ireland populationⁱ. The NIHRC has noted during the consultation process on the June 2010 UK budget, that one of the central aims of the reform of DLA was to reduce the cost of the benefit by 20%. Reform of the DLA system therefore could result in many thousands of disabled people in Northern Ireland losing entitlement to this benefit or receiving reduced support. Since DLA aids disabled people's personal mobility, helps them to lead an independent life in the community and for some helps achieve an adequate standard of living, withdrawal of the benefit is likely to result in regression, rather than the progressive realisation of their human rights".

The IMNI also commented that Article 19 also relates to traditional civil and political rights that must be realised without delay, for example, non-discrimination with regards to access by disabled people to community services, and concluded that it would not be appropriate to examine the implementation of Article 19 by solely focusing on socio-economic issues.

5.15.4. Results from the questionnaire and the focus groups

Independent living was rated as the second most important gap area by disabled people in the conference questionnaire (n=10), the 6th area for non disabled respondents (n=18) and the 4th most important area for the full number of respondents to this question (n=28). Full details are contained in Paragraph 3.12 Appendix 1.

There are few direct comments either from the questionnaire or the focus groups, which may in part be due to the complex nature of this Article, with comments ranging from the difficulties in getting loans to transportation. Comments are therefore contained in several Articles of this report, primarily in Article 26.

5.15.5. General comment

While a more detailed exploration of the area of independent living would be advantageous, it is considered outside the scope and timeframe of the present study. This is due to the complex nature of the interaction of a number of Departments and policies and other factors including; the absence of the review by the Northern Ireland Executive as recommended by the PSI report; the non availability of the State (OFMdFM) report; the ongoing investigation by the Parliamentary Joint Committee on Human Rights, and the recent legislative problems in relation to direct payments highlighted by the judicial review.

5.16. Article 20 Personal mobility

Article 20 - Personal mobility

States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:

- (a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;
- (b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including making them available at an affordable cost;
- (c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;
- (d) Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

Article 20 requires States Parties to take 'effective measures' to ensure personal mobility for persons with disabilities. A non-exhaustive range of measures is provided in Article 20 (a) to (d). Measures required under this article should include:

- Facilitating the personal mobility of persons with disabilities (i) in the manner and (ii) at the time of their choice and (iii) at an affordable cost;
- Facilitating access by persons with disabilities to: (i) quality mobility aids, devices and assistive technologies (ii) forms of live assistance and intermediaries. The facilitation of the latter (mobility aids etc) should include making them available at affordable cost;
- Providing training in mobility skills to persons with disabilities and specialist staff working with persons with disabilities;
- Encouraging entities that produce mobility aids etc to take into account 'all aspects of mobility for persons with disabilities'.

5.16.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 20 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures to facilitate the personal mobility of persons with disabilities, including the use of signal indicators and street signs for accessibility, in the manner and the time of their choice, as well as their access to forms of assistance (human, animal, or assistive technologies and devices), at an affordable cost;
- Measures taken to ensure that the technologies are high quality, affordable, and user-friendly;
- Measures taken to give training in mobility skills to persons with disabilities and specialist staff;
- Measures taken to encourage entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.

5.16.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

A range of State and Territory aids and equipment programs are available in **Australia** to ensure more consistent access to aids and equipment for persons with disabilities in line with Article 20 of the UNCRPD. New South Wales have an 'Enable NSW' service which provides appropriate assistive technology in the areas of core communication, mobility, respiratory function and self-care. Victoria's 'Aids and Equipment Program' provides persons with a permanent or long-term disability with subsidised aids and equipment to enhance independence in their home, facilitate community participation and support families and carers in their role. A 'Medical Aids Subsidy Scheme' is available in Queensland and provides access to subsidy funding for the provisions of aids and equipment to Queensland residents with permanent and stabilised conditions or disabilities, to assist them to live at home and avoid premature or inappropriate residential care or hospitalisation. The

‘Northern Territory Independence and Mobility Scheme’ provides equipment to people to assist with their independence, ranging from specialised electric wheelchairs to continence equipment. Furthermore, a number of State and Territory aids and equipment programs include the provision of access to specialised software and hardware to allow persons with disabilities to access computers and internet.⁴⁰⁰

The **Austrian** Federal Ministry of Transport, Innovation and Technology have set up a strategic research promotion programme IV2S Plus which promotes themes such as social inclusion, equal opportunities and accessibility. Concerning air passengers a barrier-free complaints facility has been set up on the website with information on air passenger rights. The theoretical driving license examination can be taken by means of a DVD for people who are deaf or hard of hearing. Financial support is offered to blind people and those with severely impaired vision (blind person’s allowance, guide dog allowance) and high-quality mobility aids, devices, supporting technologies and human / animal help are financed. In addition, underground stations, buses and pedestrian crossings have been adapted to become completely barrier-free.⁴⁰¹

In its shadow report on **Spain**, CERMI has called on projects for works and activities on the public roadways to include the necessary provisions for accessibility to ensure the security of persons with disabilities. With regard to air travel CERMI have requested that restrictions hindering certain passengers with disabilities from travelling alone be removed, or the necessary measures to be adopted to prevent discrimination or financial injury. Also any prohibition or restriction to the ability of persons with disabilities travelling in a group should be removed. Furthermore, CERMI require community regulations to be looked at with regard to the UNCRPD to specifically regulate the way the support products and technical aids of persons with disabilities are dealt with when damaged, mislaid or lost by the airline. At present such products are simply considered baggage, but their functions and value are very different.⁴⁰²

5.16.3. Key policies and programmes in Northern Ireland relevant to Article 20

Personal mobility has a crucial role in empowering disabled people to achieve independence, participate more fully in life and experience greater social inclusion. It encompasses many factors including accessible

⁴⁰⁰ CRPD/C/AUS/1, ‘Report to the Committee on the Rights of Persons with Disabilities: Australia’ (3 December 2010), at para 127-128

⁴⁰¹ CRPD/C/AUT/1, ‘Report to the Committee on the Rights of Persons with Disabilities: Austria’ (2 November 2010), at 29-30.

⁴⁰² CERMI, ‘Human Rights and Disability: Spain Report 2009’, 27 May 2010, at 31.

transport, assistance including care provision and assistive equipment and must incorporate personal choice in all aspects of life including education, transport and family life.

In recognising the 'differences amongst disabled people in the types of transport options, assistance and choice they need, the relevant Departments must ensure that the views and concerns of disabled people are sought from an early stage. By contributing to the design stage of service provision, disabled people can have a voice and consequently, an influence over their own lives'. A good example of this process is the current research project by the Northern Ireland Housing Executive (NIHE) on adaptive technologies for the home.⁴⁰³ The NIHE is working with disabled people, Disability Action, manufacturers and other professionals to examine better ways to provide disabled people with the assistive technologies they need and to involve them at the beginning of the design and fitting process.

In relation to transport, the PSI report comments that a third of respondents, when questioned had noticed an improvement in physical access to public transport facilities within the last 5 years.⁴⁰⁴ This improvement may be due largely to the Accessible Transport Strategy, which since its introduction in 2005, has sought to address the main barriers to travel for people with disabilities and older people, and "to have an accessible transport system that enables older people and people with disabilities to participate more fully in society, enjoy greater independence and experience a better quality of life".⁴⁰⁵ The latest action plan⁴⁰⁶ continues in the development of this strategy.

Access to information is essential and difficulties in relation to this have been explored under Article 9. There have however been notable examples of good practice in the provision of accessible transport information in recent years, for example the Translink Access Guide developed by the Inclusive Mobility and Transport Advisory Committee (IMTAC)⁴⁰⁷, the ECNI transport guides⁴⁰⁸ and Translink and the Consumer Council guide to air travel⁴⁰⁹

⁴⁰³ <http://www.disabilityaction.org/fs/doc/publications/products-working-group-leaflet.pdf>

⁴⁰⁴ OFMdFM (2009) 'Report of the Promoting Social Inclusion Working Group on Disability': OFMdFM: Belfast.

⁴⁰⁵ Department of Regional Development for Northern Ireland (2005) 'An Accessible Transport Strategy for Northern Ireland', Page 12. See http://www.drndi.gov.uk/accessible_transport_strategy_for_northern_ireland_2015-10.pdf.

⁴⁰⁶ Department of Regional Development for Northern Ireland, Accessible Transport Strategy, Action Plan 2009-2012. See http://www.drndi.gov.uk/accessible_transport_s_strategy_action_plan_2009-2015.pdf

⁴⁰⁷ <http://www.imtac.org.uk/>

⁴⁰⁸ http://www.equalityni.org/sections/default.asp?secid=4&cms=Service+Providers_GFS+consultations&cmsid=130_686&id=686

⁴⁰⁹ <http://www.consumerCouncil.org.uk/filestore/documents/Access%20to%20air%20version%202.pdf>

however problems remain. In 2006, IMTAC highlighted ongoing problems such as small text sized timetables and inaccessible websites. IMTAC report⁴¹⁰ that they intend to re-examine the issues involved during their current work cycle and this is welcomed.

Recent changes in legislation such as the Disability Discrimination (Transport Vehicles) Regulations (Northern Ireland) 2009 have positively changed policies and practices in the area of transport, notably in relation to air travel, taxis and transport operators. However problems remain and there have been anecdotal reports of an increase in fares from taxi companies since the regulations changed. One participant from the focus groups commented;

“Wheelchair users can pay 1.5 to 2 times normal fare to use taxis despite new taxi regulations. Are operators and disabled people aware of the regulations?”⁴¹¹.

The PSI report also reported other notable achievements including:

- The expansion of concessionary fares to more groups of disabled people;
- An increase of accessible buses and trains;
- The installation of an audio/visual announcement system on all new trains;
- The expansion of a door-to-door service in urban areas; and
- The Baywatch campaign to highlight the abuse of designated parking spaces for disabled people.

While recognizing these improvements the PSI Report also emphasised that much has yet to be done. It highlighted opportunities afforded by improving technology such as the benefits of the audio/visual announcement system which has been installed on all new trains. The report commented that a similar system should be introduced into buses and bus stops so that a choice of transport options is available to people with disabilities and to provide timetable information and route planning.

The report also recognised that the provision of an accessible transport system was not merely about the provision of physically accessible vehicles but should also seek to break down every barrier that may hinder disabled people from using it. For example, the Northern Ireland Survey of Activity Limitation and Disability (NISALD survey)⁴¹² identified that 83% of respondents said they rarely or never use public transport and of those that do, 16% said they had experienced difficulties in the 12 months prior to

⁴¹⁰ Conversations with IMTAC during the Spring 2011

⁴¹¹ Comment from a participant in the Thematic Focus Group Workshop on the 18th February 2010, Article 9 and 21 ‘Access to information’ and Article 31 on ‘Statistics and Data Collection’

⁴¹² NISRA (2007). Northern Ireland Survey of Activity Limitation and Disability NISRA: Belfast

being interviewed. This would suggest that there are additional factors that should be considered in order to attain a completely accessible transport system. Research from the Consumer Council in 2009⁴¹³ suggests awareness of disability, staff training, and verbal and electronic updates at stations are required.

Issues identified from the research included, drivers not recognising disabilities such as blindness and not offering the appropriate help to blind people when buying tickets; drivers not stopping for people who are blind or have other disabilities; no enforcement of priority seats for the elderly and disabled; and staff not trained in the operation of equipment meant to make buses more accessible.

“More can be done in terms of staff being more sensitive to the needs of older people.”⁴¹⁴

The PSI report summarised the difficulties in relation to mobility when it commented that some of the difficulties involved in the mobility of disabled people were due to the following factors:

- The attitudes of people and society, service design, and the availability of accessible information;
- Inconsistencies in the travel chain of journeys, for example in town planning where uneven pavements and street furniture can often prove problematic for disabled people trying to complete a journey. It was recommended that public spaces and indeed transport services should be designed to adapt to the particular needs of individuals and that services such as Shopmobility NI should be incorporated into the design and planning of transport stations and shopping centres developed within town centres;
- Not considering disability at an early stage when designing travel systems including training. It recommended greater co-operation between the agencies involved which it commented was particularly essential with regard to the location of static street furniture
- It commented that the voluntary and community sector should encourage organisations to go beyond merely complying with the DDA and consider access issues from the view point of disabled people;
- More appropriate service for rural areas involving door-to-door services and community transport;
- More choice through increasing the number of accessible taxis;

⁴¹³ Consumer Council (2009) Public Transport on the Right Track? http://www.consumercouncil.org.uk/filestore/documents/Final_PT_report_05.06.09.pdf

⁴¹⁴ Ibid

- Increased knowledge of the Concessionary Fares Scheme. More than half of disabled people surveyed through NISALD were not aware that concessionary rates are available for disabled people when using public transport. It was recommended that more accessible information be made available;
- In summary the PSI report suggested that a variety of services could be delivered in a more tailored way. The mainstreaming of disability considerations into planning and design can achieve positive outcomes for disabled people through supporting them to empower themselves to live more independent, participative lives.

5.16.4. Results from the questionnaire and the focus groups

These findings mirror findings from the focus groups and conference questionnaire which are listed below;

“Public transport needs to be looked at, as I said before about Translink. I think also NI Railways don’t always have a disabled carriage on the train. I think you have to tell them you’re travelling, so someone in a wheelchair can’t just go to the station on a whim and decide to get on a train because there would be more than likely no disabled carriage on the train”.

“Public transport should be accessible for disabled people. There should be a designated area for people with disabilities, and their carers or the elderly that no one else can use”.

“Disability Awareness training of frontline staff in transport - there is policy but how do you change things that aren’t working?”

“Raise awareness (transport timings, tactile markings on road) requirement for more participation of disabled people.”

“Whilst DDA is welcome and has resulted in significant change in accessibility for people with disabilities - unfortunately when you are in a wheelchair or in a major buggy, as is my son, things are not seamless. Things take longer, moving around in busy areas like shopping centres is a nightmare, you still feel like a poor relation as you are shown in by the back door all too often”.

“Is there a travel policy for disabled people in terms of a break in the travel chain system such as a train breakdown? In other words what does a wheelchair user do if passengers need to disembark?”

“I am a carer and look after someone who is disabled (in a wheelchair) and have had experience of a barrier as I was with the disabled person at the time. Translink refused the disabled person I was with access onto their bus as people who had prams were in the area that clearly states for elderly and disabled people. It also states that any passenger who is not disabled or elderly may be asked to vacate the area to allow disabled or elderly on. On this particular day, myself and the person I was looking after who was in a wheelchair were denied access. The bus driver did ask the person to move but he wouldn't and the bus driver said we would have to wait on the next bus. When the next bus came the same thing happened people with prams were in the disabled area and we were denied access and had to wait on a third bus!! If it clearly states that the designated area on the bus is for disabled or elderly then that should be the case and if people with prams don't move they should be asked to leave the bus or be fined. Translink's answer to this situation was that the bus driver can only ask the people with prams to move if they refuse he can't make them. My answer to this is then why have an area specifically for elderly and disabled if anyone can use it and disabled people are refused access”.

5.17. Article 21: Freedom of expression and opinion and access to information

Article 21 - Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in Article 2 of the present Convention, including by:

- (a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

- (b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
- (c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- (d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- (e) Recognizing and promoting the use of sign languages.

Article 21 requires States Parties to take 'all appropriate measures' to ensure that persons with disabilities can exercise the right to freedom of expression and opinion. This is importantly stated to include the freedom to seek, receive and impart information and ideas 'on an equal basis with others'. Article 21 is also explicit in clarifying that its obligations include the use of 'all forms of communication of their choice as defined in Article 2'.

Article 2 of the Convention defines 'communication' as including:

- languages (defined in Article 2 of the Convention to explicitly include 'spoken and signed languages and other forms of non-spoken languages');
- Braille;
- tactile communication;
- large print;
- accessible multimedia;
- written, audio, plain language, human reader and augmentative and alternative modes, means and formats of communication and accessible information and communication technology.

Article 21 (a) to (e) provides examples of some of the 'appropriate measures' that States Parties are expected to take in order to meet their obligations under this Article. These are not intended to be exhaustive and are:

- provide information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

- accept and facilitate the use of the range of formats of communication defined by the Convention in 'official interactions';
- urge private entities that provide services to the general public to provide information and services in accessible and usable formats;
- encourage the mass media to make their services available to persons with disabilities;
- recognise and promote the use of sign languages.

5.17.1. Consideration of other UN human rights treaties

In the context of children, the Committee on the Rights of the Child has stated that children need access to information in formats appropriate to their age and capacities on all issues of concern to them. This applies to information, for example, relating to their rights, any proceedings affecting them, national legislation, regulations and policies, local services, and appeals and complaints procedures.⁴¹⁵

The Committee on the Rights of the Child has also stated that freedom of expression relates to the right to hold and express opinions, and to seek and receive information through any media. It asserts the right not to be restricted by the State party in the opinions she or he holds or expresses. As such, the obligation it imposes on States Parties is to refrain from interference in the expression of those views, or in access to information, while protecting the right of access to means of communication and public dialogue.⁴¹⁶

5.17.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 21 in the Guidelines on treaty specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to ensure that information provided to the general public is accessible to persons with disabilities in a timely manner and without additional cost;
- Legislative and other measures taken to ensure that persons with disabilities can use their preferred means of communication in all forms of official interaction and access to information, such as sign language, Braille, augmentative and alternative communication, and all other accessible means;

⁴¹⁵ Committee on the Rights of the Child (2009) General Comment 12: 'The right of the child to be heard', at Para 82

⁴¹⁶ Committee on the Rights of the Child (2009), General Comment 12: 'The right of the child to be heard' at Para 81

- Measures taken to urge private entities and mass media to provide their information and services in an accessible form for persons with disabilities, including measures taken to prevent the blocking or restriction of access to information in alternative formats by the private sector;
- Degree of accessibility of mass media and percentage of public websites that comply with the Web Accessibility Initiative (WAI) standards;
- Measures taken linked to the official recognition of sign language(s).

5.17.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

Under Article 21 of the UNCRPD, **Australia** reports that it has introduced 'World Wide Web Consortium Web Content Accessibility Guidelines' which all government agencies and departments are required to comply with. The Australian government funds 'Media Access Australia' to caption uncaptioned educational and community DVDs and downloadable versions for people who are deaf or hearing impaired. They also fund 'Nican Incorporated' to provide an accessible website with information about travel, sport and recreational opportunities for persons with disabilities. In addition, a 'Print Disability Services Program' is funded by the Australian government which produces digital masters of print material in a file format that can readily be converted into a range of alternative formats for persons with a print disability.⁴¹⁷

Tunisia reports that the State provides resources and equipment in order to encourage the media to disseminate social and cultural programming to persons with disabilities. Persons with disabilities have been involved in making radio and television programmes. Sign language has been introduced for news programmes, and subtitling is in use for other television programmes. Tunisia has established 24 media and communication units with disabled-friendly equipment, one in each province. The units provide several long-distance services, including communications and electronic, internet and media services. They can assist with a range of social issues,

⁴¹⁷ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 129-131

inquires and services. A website for persons with disabilities has been created and Tunisia is in the process of modifying all administrative websites in order to make them disabled-friendly. This has been encouraged through grants being offered to associations wishing to create such websites. Additionally, a national media centre for children with disabilities has been established and disabled persons are entitled to a discount on internet services.⁴¹⁸

In its shadow report on Spain CERMI has stressed the importance of public and large company websites complying with accessibility conditions in order to assist in ensuring that States are satisfying their obligations set out in Article 21 of the UNCRPD.⁴¹⁹

5.17.4. Key policies and programmes in Northern Ireland relevant to Article 21

The particular obligations under this Article with respect to policies and programmes are considered under Article 9 for ease of discussion. However two obligations contained in this Article relating to alternative communication under Article 21(b) and the obligation under Article 21(e) and Article 24(4) in relation to Sign Language, Braille and education require further short discussion.

5.17.4.1. Article 21(b)

The requirements under 21(b) 'accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions', will require considerable coordination across all departments of the State. It will also require discussions with the monitoring body for disability legislation as to this Article's relationship with the reasonable adjustment concept under the DDA. The Article is quite clear in its expectations of the State and from the current position in Northern Ireland as detailed in Article 9 (for example with the lowest internet use for disabled people in the UK) and other Articles in this report (see for example Article 11) considerable work will have to be undertaken. Some examples of good practice are available from other jurisdictions, notably Scotland where people with disabilities and groups are working with the Government to create a new national statement of inclusive communication principles and indicators to measure progress. Once completed, that will offer a practical approach to delivering inclusive communication.

⁴¹⁸ CRPD/C/TUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Tunisia' (14 July 2010), at para 136-148.

⁴¹⁹ CERMI, 'Human Rights and Disability: Spain Report 2009', 27 May 2010, at 31.

5.17.4.2. Sign Language

In Northern Ireland the RNID estimates that there are approximately 258,510 deaf and hard of hearing people. There are 17,000 people who are severely or profoundly deaf. There are 241,510 people who are hard of hearing and 41.7% of people over 50 years old will have some kind of hearing loss, rising to 71.1% for those over 70 years old. There are approximately 178,900-357,800 people with tinnitus and tinnitus severely affects the quality of life of 8,945 people.⁴²⁰

On the 29 March 2004, both British Sign Language (BSL) and Irish Sign Language (ISL) were formally recognised as languages in their own right by Paul Murphy, Secretary of State for Northern Ireland.

Following this recognition, the Department for Culture, Arts and Leisure (DCAL) established a Sign Language Partnership Group. This group brings together Government departments and organisations representing people who are deaf. Its principal aim is to enhance the number of deaf tutors and qualified (BSL) and (ISL) Sign Language Interpreters in Northern Ireland.

In June 2008, the Department of Employment and Learning (DEL) allocated £1.3m over 3 years to increase the number of deaf tutors and qualified (BSL) and (ISL) Sign Language Interpreters.

Presently there are 11 fully qualified, registered Sign Language Interpreters in Northern Ireland and 7 Junior Trainee Interpreters. It is estimated however, that Northern Ireland requires in excess of forty fully qualified, registered Sign Language Interpreters to meet the access needs of people who are deaf and to be in line with some of the better practice in other European countries⁴²¹.

The shortage of Sign Language Interpreters in Northern Ireland, including Performance Interpreters, has the potential to exclude access for people who are deaf to a range of facilities and services, thus contravening a number of articles in the Convention⁴²² notably Articles 29, 9, 24 and 25.

For example, in order to help ensure the realisation of Article 24(4) on Education, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/ or Braille. Further, professionals and staff who work at all levels of education must be appropriately trained. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

⁴²⁰ Comment from the RNID (Action against Hearing Loss) as part of Stage 2 process 2010

⁴²¹ Annex to the Report of the Promoting Social Inclusion Working Group on Disability

⁴²² Comment from RNID (Action against Hearing Loss) as part of Stage 2 process

This research has not found any statistics in relation to the number of suitably qualified professional or staff in Northern Ireland and an examination of the Department of Education for Northern Ireland (DENI) Draft Disability Action Plan 2010 – 2013 did not reveal any action plan on the matter. However, it is noted that in action point 15 in the DENI Disability Action Plan, the Department will review arrangements for communication between schools and deaf or hard of hearing parents by March 2011, although no specific plans or targets are indicated.

5.17.5. Results from the questionnaire and the focus groups

Comments in relation to this Article from the conference questionnaire and the focus group are contained in the section on Article 9.

5.18. Article 22: Respect for privacy

Article 22 - Respect for privacy

- 1 No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks.
- 2 States Parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

Article 22 imposes a obligation on States Parties to ensure that no person with disabilities is subjected to unlawful or arbitrary interference with their 'privacy, family, home, or correspondence'. Article 22 (1) also protects from interference with 'other types of communication' and this phrase should be interpreted as defined in Article 2 of the Convention. Article 22 (1) on respect for privacy emphasizes that the obligation on States Parties to respect privacy, as broadly conceived, applies 'regardless of place of residence or living arrangements'. This is a highly important phrase as it means that this right is not subject to modification on the grounds that a person with a disability lives in a particular kind of residential setting such as a hospital or community-based living arrangement. There must be policies in place to ensure that their right to privacy is also protected in an effective manner

within such settings. This is effectively a broad definition of 'home' than the ordinary meaning of the term to ensure the equal protection of the rights of persons with disabilities.

Article 22 (2) singles out one area for special mention namely, the protection of the privacy of personal, health and rehabilitation information 'on an equal basis with others'. This protection of informational privacy will require effective policies and any programmes which collect information shall respect the right to privacy of persons with disabilities.

5.18.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 22 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to protect the privacy of personal, health and rehabilitation related information of persons with disabilities;
- Measures taken so that persons with disabilities not be concealed on the pretext of protection of privacy.

5.18.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

In its shadow report on the State Report of **Tunisia**, the International Disability Alliance (IDA) has highlighted that measures should be in place which allow persons with disabilities to access and correct their medical records, including mental health records. Additionally, policies and programmes should ensure that the privacy of persons with disabilities who live in large or small institutions or who rely on a high level of support services is respected on an equal basis with the privacy of others in the general population.⁴²³

⁴²³ International Disability Alliance, 'Submission on List of Issues for Tunisia: Committee on the Rights of Persons with Disabilities', October 2010, at 7.

5.18.3. Key policies and programmes in Northern Ireland relevant to Article 22

Article 22 deals with 'respect for privacy'. Across the UK there are a very wide range of laws, policies and programmes which enforce respect for the privacy of disabled people. These include:

- those created to meet the obligations of the Human Rights Act;
- those created to meet the obligations of the Data Protection Act;
- policies and programmes of the police and security services;
- the common law on confidentiality;
- 'ethical' policies of regulators (such as the Northern Ireland Social Care Council or the General Medical Council);
- the statutory powers of the National Human Rights Institutions (NHRIs);
- the statutory powers of the Information Commissioner; and
- programmes of education and training, including training on the importance of privacy across the full range of health and social care staff.

The content of Article 22 adds little to the existing human rights obligations with respect to privacy and is addressed overwhelmingly at a UK level and for the population as a whole and is therefore not a key area with respect to implementation of the CRPD specifically within Northern Ireland. The truly vast range of policies and programmes engaged by this Article also preclude it being examined in depth given the scope of this project.

5.18.4. Results from the questionnaire and the focus groups

The only result in relation to this Article was in the Conference workshop in which a particular group, rated privacy and sharing, as part of a key 'access' barrier to people with disabilities fully participating in society in Northern Ireland

This was not clarified by any other comments in the questionnaire or any of the focus groups but may form part of independent living under Article 19 (a) and Article 23 in relation to the living arrangements a person may make

5.19. Article 23: Respect for home and family

Article 23 - Respect for home and the family

- 1 States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
 - (a) The right of all persons with disabilities, who are of marriageable age, to marry and to found a family on the basis of free and full consent of the intending spouses is recognised;
 - (b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights are provided;
 - (c) Persons with disabilities, including children, retain their fertility on an equal basis with others.
- 2 States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.
- 3 States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realising these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.
- 4 States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such

separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.

- 5 States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

Article 23(1) requires States Parties to take 'effective and appropriate measures' to eliminate discrimination against persons with disabilities in all matters related to marriage, family, parenthood and relationships, 'on an equal basis with others'. It is clearly intended to have a broad coverage as the use of 'all matters' makes clear. The meaning of 'discrimination', the elimination of which Article 23 aims for, is given by reading Article 23 in the light of Articles 2, 3 and 5. This Article is expanded on in 23(1) (a), (b) and (c) which articulate what the measures must ensure.

Article 23(1) (a) precludes States Parties having policies which prevent persons with disabilities marrying and founding a family 'on the basis of free and full consent'. The existence of any policy which imposes any requirements beyond this for persons with disabilities would clearly be a breach of Article 23.

Article 23(1) (b) requires that State Parties ensure the rights of persons with disabilities to decide on the number and spacing of their children. In addition, it requires measures to ensure access to age-appropriate information and to reproductive and family planning education. A hard obligation exists on States Parties to ensure that persons with disabilities are provided with 'the means necessary' to enable them to exercise these rights.

Article 23(2) relates to persons with disabilities as parents. It clarifies that they have the same rights and responsibilities as others when it comes to the law relating to children and policies and programmes must exist to ensure that this is in fact the case. Article 23(2) reaffirms that in all cases the best interests of the child shall be paramount. It further imposes an obligation **directly on States Parties** to 'render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities'. This hard obligation clearly requires that programmes must be in place to ensure that such assistance is provided and this assistance should effectively address the full range of 'responsibilities'.

Article 23(3) requires States Parties to ensure that children with disabilities have equal rights with respect to family life. It imposes clear and specific

obligations on States Parties in terms of policies and programmes in order to 'prevent concealment, abandonment, neglect and segregation'. In particular, measures are required to provide to children with disabilities and their families:

- information;
- services; and
- support.

All three of these must be both 'early' and 'comprehensive'.

Article 23(4) imposes an absolute ('in no case') prohibition on the separation of a child from parents on the basis of a disability of the child or one or both parents. This requires clear enforcement throughout a wide range of policies.

Where the immediate family is unable to care for a child with disabilities, Article 23(5) requires State Parties to undertake 'every effort' to ensure provision of care for a child with disabilities within the wider family or 'within the community in a family setting'.

5.19.1. Consideration of other UN human rights treaties

Article 23 of the International Covenant on Civil and Political Rights recognises that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State. However, the Committee on Economic, Social and Cultural Rights notes that the concept of the family may differ in some respects from State to State, and that it is therefore not possible to give the concept a standard definition.⁴²⁴ Moreover, that ensuring protection for the right to marry and found a family requires States Parties to adopt legislative, administrative or other measures, which includes policies and programmes. The Committee has also stipulated that States Parties should ensure that social policies, programmes, and practices do not impede the realisation of the right to marry and found a family.⁴²⁵

The Committee on the Rights of the Child recommends that organisations responsible for foster placement of children must conduct the necessary training and encouragement of suitable families and provide the support that will allow the foster family to appropriately take care of the child with a disability.⁴²⁶

⁴²⁴ Committee on Economic, Social and Cultural Rights (1990) General Comment 19: 'The family', at Para 2

⁴²⁵ Committee on Economic, Social and Cultural Rights (1995) General Comment 5: 'Persons with Disabilities', at Para 30.

⁴²⁶ Committee on the Rights of the Child 43rd session (2006), at Para 46.

5.19.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 23 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to ensure that persons with disabilities may exercise the right to marry and to found a family on the basis of full and free consent;
- Measures taken so that persons with disabilities have access to family planning, assistive reproduction and adoption or fostering programmes;
- Measures taken to ensure that parents with disabilities, who so require, are provided with the adequate support in their child-rearing responsibilities, ensuring the parent-child relationship;
- Measures taken to ensure that no child is separated from her/his parents because of the disability of either the child or one or both of the parents;
- Measures taken to support fathers and mothers, and the families of boys and girls with disabilities, in order to prevent concealment, abandonment, neglect or segregation of the boy or girl with a disability;
- Measures taken to avoid institutionalisation of boys and girls with disabilities whose parents are unable to care for them, and ensure that they are provided with alternative care from the wider family, or when this is not possible, in a family setting in the wider community;
- Measures taken to prevent the forced sterilisation of persons with disabilities, especially with girls and women.

5.19.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

Australia reports that it provides support for parents, families and carers of young persons with a disability through the 'Respite Support for Carers of Young People with Severe or Profound Disability Program' and 'My Time Peer Support Groups for Parents of Young Children with Disability Program'. The

Respite Support Program facilitates access to information, respite care and other assistance appropriate to the individual needs and circumstances of both carers and care recipients.⁴²⁷

With respect to Hong Kong, **China** reports that it caters for family needs through the provision of a continuum of preventative, supportive and remedial services to ensure that parents with disabilities are provided with adequate support in their child-rearing responsibilities, that no child is separated from his/her parents because of the disability of either the child or one or both of the parents unless the separation is for the benefit of the child, and to prevent concealment, abandonment, neglect or segregation of children with disabilities. The government have facilitated this through providing 'Integrated Family Service Centres', parent education, 'Residential Child Care Services' and 'Day Child Care Services'.⁴²⁸

5.19.4. Key policies and programmes in Northern Ireland relevant to Article 23

Article 23 cuts across aspects of Articles 6 and 7 in that it is concerned with reproductive rights, and with issues around safeguarding children, ensuring that 'the best interests of the child shall be paramount'. It requires that State Parties take appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships...rendering appropriate assistance (childrearing) to persons with disabilities, provide early and comprehensive support and information to prevent family breakdown and to provide alternative appropriate care where a family is unable to care for a child with disabilities.

5.19.4.1. Access to maternity services, family planning and reproductive rights

For more information see comments under Article 6.

5.19.4.2. Ensuring children with disabilities have equal rights with respect to family life

Understanding the Needs of Children in Northern Ireland (UNOCINI) guidance⁴²⁹ is a key policy document which identifies Northern Ireland assessment criteria in relation to children's welfare and the provision of

⁴²⁷ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 138-139.

⁴²⁸ CRPD/C/CHN/1/Add.1, 'Report to the Committee on the Rights of Persons with Disabilities: Hong Kong' (30 August 2010), at para 23.1-23.18.

⁴²⁹ UCOINI (2008) Understanding the Needs of Children in Northern Ireland http://www.welbni.org/uploads/file/pdf/unocini_guidance_043651.pdf

gateway services to provide support and assistance where welfare is deemed to be falling short. Specific guidelines are included for assessment of children in special circumstances, including particular attention to a holistic and multidisciplinary assessment with inclusion of medical specialists. The OFMDFM Action Plan 2008-2016⁴³⁰ 'Our Children and Young People - Our Pledge', specifically aims to improve respite packages and to create new or enhanced respite packages by 2011 for sensory and learning disability.

5.19.4.2.1. Child rearing responsibilities

The UNOCINI assessment is relevant in relation to providing appropriate assistance to people with disabilities with child-rearing responsibilities and ensuring a child is not separated from the parents by reason of disability (parental or child) and unless legally required.

Within a UNOCINI assessment, the parent's capacity is assessed under four criteria: stability, emotional warmth, basic care and ensuring safety, and guidance, boundaries and stimulation. With regard to provision of assistance with childrearing we would therefore expect to see provision in place to assist parents with disabilities where their disabilities mean they are encountering barriers in providing aspects of this care. The Carers and Direct Payments Act (Northern Ireland) 2002⁴³¹, for example, allows provision for parents with disabilities to get direct payments where care provision is needed for their child, thus providing opportunity to create more stability in relation to the number and frequency of carers. Baseline 2008/09 figures for UK⁴³² show that 13.8 per cent of adults with a physical disability received direct payments compared to 13.1 per cent of adults with a learning disability and 3.2 per cent of adults with a mental health condition. However it must be noted that Northern Ireland, alongside Wales, lacks a national independent living strategy (unlike England and Scotland)⁴³³ to implement programmes which allow choice and control over flexible services for parents with disabilities who require support and provision with regard to their family.

UNOCINI has no specific guidance in relation to parents with disabilities excepting the allowance of composite family support pathways, allowing disability and children's sector to work in a combined manner. The criteria provision for home help assessment makes no differentiation in provision for a single person with a disability or a single parent with a disability.⁴³⁴

⁴³⁰ http://www.ofmdfmi.gov.uk/draft_action_plan_2008-2013.doc

⁴³¹ <http://www.legislation.gov.uk/ni/2002/6/contents>

⁴³² <http://odi.dwp.gov.uk/roadmap-to-disability-equality/indicators.php>

⁴³³ <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/right-of-disabled-people-to-independent-living-call-for-evidence/>

⁴³⁴ http://www.dhsspsni.gov.uk/eccu_home_help_circular_-_2010.pdf

5.19.4.3. The right of persons with disabilities to enter consenting marriage

No specific policies or programmes have been found in this area. It should be noted that ground level policies by supported living providers do not admit married /co-habiting couples into their supported living programmes. These are outside the remit of the Trusts.

5.19.4.4. The right to retain fertility

No specific policies or programmes have been found in relation to this issue.

5.19.5. Results from the questionnaire and the focus groups

The importance of attitudes within families and faith beliefs was stressed by participants in the focus groups and these comments have been reported in Article 8.

A comment was received from a participant in the focus group on Access to Maternity Services Family Planning and Reproductive Rights and this is contained in Article 6.

5.20. Article 24: Education

Article 24 - Education

- 1 States Parties recognise the right of persons with disabilities to education. With a view to realising this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:
 - (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
 - (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
 - (c) Enabling persons with disabilities to participate effectively in a free society.

- 2 In realising this right, States Parties shall ensure that:
 - (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
 - (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
 - (c) Reasonable accommodation of the individual's requirements is provided;
 - (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
 - (e) Effective individualised support measures are provided in environments that maximise academic and social development, consistent with the goal of full inclusion.
- 3 States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
 - (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
 - (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
 - (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deaf blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximise academic and social development.

- 4 In order to help ensure the realisation of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.
- 5 States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.

Article 24 recognises the right of persons with disabilities to education. It is important to note that this article extends to 'persons with disabilities' without qualification on the basis of age; that is, it is a right accorded to both children and adults. In order for this right to be realised without discrimination and 'on the basis of equal opportunity', States Parties are obliged to ensure 'an inclusive education system' at 'all levels' and 'lifelong learning'. The meaning of discrimination can be ascertained by reading Article 24 in light of Articles 2 and 5.

Article 24(1) sets out the aims of education. These aims provide a standard by which policies and programmes relating to education can be determined by the State Party. The aims of an inclusive education system are fourfold:

1. The full development of human potential and sense of dignity and self-worth;
2. Strengthening of respect for human rights, fundamental freedoms and human diversity;
3. The development by people with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential; and
4. Enabling people with disabilities to participate effectively in a free society.

Article 24(2) elaborates further on the obligations of States Parties in respect of the right to education for persons with disabilities by listing the things they must 'ensure'. These obligations provide a checklist against which policies and programmes can be measured as sufficient for the fulfilment

of the obligations of this right. Specifically States Parties must ensure that (including through policies and programmes):

- Persons with disabilities are not excluded from the general education system on the basis of disability;
- Children with disabilities are not excluded from free and compulsory primary or secondary education on the basis of disability;
- Persons with disabilities can access an 'inclusive', 'quality' and 'free' primary education and secondary education on an equal basis with others in the communities in which they live;
- Reasonable accommodation of the individual's requirements is provided;
- Persons with disabilities receive the support required, within the general education system, to facilitate their 'effective education';
- Effective individualised support measures are provided in environments that 'maximise academic and social development'. These environments should be 'consistent with the goal of full inclusion'.

A definition of the nature and extent of reasonable accommodation can be found in Article 2, CRPD. It is important to note in respect of the above that the State Party is not simply obliged to provide individualised support measures, but to provide individualised support measures which are 'effective'. It is also important to note that the obligations of a State Party to ensure that persons with disabilities are not excluded from the general education system; to provide individualised support measures, and to provide reasonable accommodation, extends to both compulsory and non-compulsory education.

Article 24(3) obliges States Parties to 'enable' persons with disabilities to learn life and social development skills to 'facilitate' (not ensure) their full and equal participation both in education and as members of the community. To fulfil this obligation, States Parties are required to take measures which are 'appropriate'. These measures, which will include policies and programmes, should include (but not be restricted to)

measures which facilitate (but not ensure) the learning of:

- Braille;
- Alternative script;
- Augmentative and alternative modes, means and formats of communication;
- Orientation and mobility skills;
- Peer support and mentoring;
- Sign language.

States Parties are also required to take measures (which will include policies and programmes) to promote the linguistic identity of the deaf community, and measures which 'ensure' that the education of persons, and 'in particular' children, who are blind, deaf or deaf blind, is delivered in the 'most appropriate' languages and modes and means of communication for the individual. This alone is not sufficient for the fulfilment of this obligation; education for these groups of people with disabilities should be provided in environments which maximise academic and social development.

Article 24(4) requires States Parties to take 'appropriate' measures, which will include policies and programmes, to:

- Employ teachers, including teachers with disabilities, who are qualified in sign language and Braille; and
- Train professionals and staff who work at all levels of education.

The latter obligation is not restricted to teaching staff, but includes professionals and staff who work at all levels of education. The remainder of this article elaborates upon the content of training programmes which would fulfil this obligation. Specifically, training programmes should 'incorporate':

- Disability awareness;
- The use of appropriate augmentative and alternative modes, means and formats of communication;
- Educational techniques to support persons with disabilities;
- Educational materials to support persons with disabilities.

Finally, Article 24(5) obliges States Parties to 'ensure' that persons with disabilities are able to access the following without discrimination and on 'an equal basis with others':

- General tertiary education;
- Vocational training;
- Adult education;
- Lifelong learning.

To fulfil this obligation, States Parties must ensure that 'reasonable accommodation' is provided to persons with disabilities. Again, the meaning of 'reasonable accommodation' should be read in light of Article 2 which defines the term.

5.20.1. Consideration of other UN human rights treaties

A general right to education for everyone was proclaimed by Article 26 of the Universal Declaration on Human Rights (UDHR) in 1948. This was reaffirmed and made binding by Article 13(1) of the International Covenant on Economic, Social and Cultural Rights (ICESCR) (1966), and elaborated

upon by Articles 28 and 29 of the Convention on the Rights of the Child (CRC) (1989).

The Committee on Economic, Social and Cultural Rights, drawing on Tomasevski's '4-A Schema'⁴³⁵ has affirmed that educational institutions and programmes for everyone should be available, accessible, acceptable and adaptable.⁴³⁶ That is, educational institutions and programmes should be available in sufficient quantity and accessible to everyone without discrimination. The form and substance of education including curricula and teaching methods should be acceptable and they should be flexible so it can respond to the needs of students within 'their diverse social and cultural settings'. Moreover, these features should be 'common to education in all its forms and at all levels'⁴³⁷ and that the prohibition against discrimination applies 'fully and immediately to all aspects of education'.⁴³⁸

'Education' in the context of the Convention on the Rights of the Child goes beyond formal schooling to embrace the broad range of life experiences and learning processes which enable all children, individually and collectively, to fully develop their personalities, talents and abilities and to live 'a full and satisfying life within society.'⁴³⁹

5.20.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 24 in the Guidelines on the treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the UNCRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to ensure that every child with disabilities has access to early-stage education, and mandatory primary, secondary and higher education.;
- Information on the number of boys and girls with disabilities in early-stage education;
- Information on the existing significant differences in the education of boys and girls in the different education levels and whether there are policies and legislation to cater for these differences;

⁴³⁵ 'Preliminary report of the Special Rapporteur on the right to education' Katerina Tomasevski (1999) at paras 42-74.

⁴³⁶ Committee on Economic, Social and Cultural Rights (1999) General Comment 13: The Right to Education (art. 13) E/C.12/1999/10 at para 6.

⁴³⁷ Committee on Economic, Social and Cultural Rights (1999) at para 7.

⁴³⁸ Committee on Economic, Social and Cultural Rights (199) at para 31. [committee/news/right-of-disabled-people-to-independent-living-call-for-evidence/](https://www.unhcr.org/refugees/committee/news/right-of-disabled-people-to-independent-living-call-for-evidence/)

⁴³⁹ Committee on the Rights of the Child (2001) General Comment 1: The Aims of Education, CRC/GC/2001/1, at para 2.

- Measures that ensure that schools and materials are accessible and that individualised reasonable accommodation and support required by persons with disabilities is provided to ensure effective education and full inclusion;
- Availability of specific skills-training services for children, adults or teachers who so require in Braille, sign languages, augmentative and alternative communication, mobility and other areas;
- Measures taken for the promotion of the linguistic identity of deaf persons;
- Measures taken to ensure education is delivered in the most appropriate languages, modes, means of communication, and environments for the individual;
- Measures to ensure an adequate training on disability to professionals in the education system, as well as measures to incorporate persons with disabilities in the education team;
- Number and percentage of students with disabilities in tertiary education;
- Number and percentage of students with disabilities by gender and fields of study;
- Reasonable accommodation provisions and other measures to ensure access to lifelong learning education;
- Measures taken by the State to ensure early identification of persons with disabilities and their education needs.

5.20.3. Key policies and programmes in Northern Ireland relevant to Article 24 Education

“Knowledge is power! – How do we educate disabled people on rights?”⁴⁴⁰

5.20.3.1. SENDO

The law dealing with education for children with disabilities in Northern Ireland is contained in the Education (Northern Ireland) Order 1996 as amended by the Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDO). The statutory responsibility for securing provision for pupils with special educational needs rests with the Education and Library Boards and Boards of Governors of mainstream schools. Currently, special educational needs provision is matched to individual need and may be made in special schools; special units attached to mainstream schools; or in mainstream classes.

⁴⁴⁰ Comment from a participant on the Thematic Focus Group on Awareness Raising on the 19/1/11

The Department of Education has provided policy guidance for Education and Library Boards and schools in the form of a Code of Practice on the Identification and Assessment of Special Educational Needs and also a Supplement to the Code of Practice, effective from 1 September 2005, which was produced as result of SENDO. Schools, Boards and health and social services authorities must consider the advice given in the Code of Practice when deciding what they should do for children with special educational needs. Under the Code of Practice, a child has a 'learning difficulty'⁴⁴¹ if:

- He/she has significantly greater difficulty in learning than the majority of children of his/her age;
- He/she has a disability which either prevents or hinders him/her from making use of educational facilities of a kind generally provided for children of his/her age in ordinary schools; or
- He/she has not attained the lower limit of compulsory school age and is, or would be if special educational provision were not made for him/her, likely to fall within either of the previous two paragraphs when he/she is of compulsory school age.

However, it is important to note that not all disabled children have special educational needs and not all children with special educational needs will have a disability raising the issue that not all children with disabilities may necessarily be protected by existing policies and programmes.

The Code of Practice defines 'special education provision' as "educational provision which is additional to, or otherwise different from, the educational provision made generally to children of this age in ordinary schools."⁴⁴²

There are currently 5 stages to the current process for the identification and assessment of special educational needs and provision:

- Stage 1: teachers identify and register a child's special educational needs and, consulting the school's SEN co-ordinator, take initial action.
- Stage 2: the SEN co-ordinator takes lead responsibility for collecting and recording information and for co-ordinating the child's special educational provision, working with the child's teachers.
- Stage 3: teachers and the SEN co-ordinator are supported by specialists from outside the school.
- Stage 4: the Board considers the need for a statutory assessment and, if appropriate, makes a multi-disciplinary assessment.
- Stage 5: the Board considers the need for a statement of special educational needs; if appropriate, it makes a statement, arranges, monitors and reviews provision.

⁴⁴¹ Department of Education (1998) Code of Practice on the Identification and Assessment of Special Educational Needs, Bangor: DE.

⁴⁴² Department of Education (1998) Code of Practice on the Identification and Assessment of Special Educational Needs, Bangor: DE.

At present there is only a statutory time frame for Stage 4 assessment and Stage 5 (statement issued). Delays in reports being forwarded by non-educational services can mean that, despite statutory time limits, these are not always adhered to. Inadequate numbers of educational psychologists coupled with a lack of statutory time limits in relation to the school based stages of the process, in particular Stage 3, has resulted in unacceptable waiting lists regionally. Difficulties arise when the quantity and type of support provision such as speech and language therapy and occupational therapy is not made explicit within Part 3 of the statement.

Reports by the Education and Training Inspectorate (ETI) have highlighted a lack of consistency in procedures/protocols for assessing need and differential thresholds for intervention in relation to the assessment and diagnosis of SEN.⁴³³ A 2007 ETI report noted particular difficulties with delay and shortcomings in the planning for and assessment of children's special educational needs in all types of pre-school provision.⁴⁴⁴

“Young children being able to access mainstream education so that they can gain an education as the rest of their peers and be able to be employed so that they can have the same standard of living as everyone else.”⁴⁴⁵

The enactment of SENDO in September 2005 has given children with SEN increased rights to be educated within mainstream settings. The Supplement to the Code of Practice elaborates further on the new duties placed on schools; that is, the duty:⁴⁴⁶

- Not to treat pupils who have a disability less favourably, without justification, for a reason which relates to their disability;
- To make reasonable adjustments so that pupils who have a disability are not put at a substantial disadvantage compared to pupils who do not have a disability; and
- To plan and make progress in increasing accessibility to schools' premises and the curriculum, and in improving ways in which information provided in writing to pupils who do not have a disability is provided to pupils with a disability.

⁴⁴³ Education and Training Inspectorate (2006a) Report of a Survey on Provision and Outcomes for Pupils with Special Educational Needs in Post-Primary Schools. Bangor: Department of Education.

⁴⁴⁴ Education and Training Inspectorate (2007a) Special Educational Needs in the Pre-School Sector. Bangor: Department of Education.

⁴⁴⁵ Response from the IMNI Conference questionnaire.

⁴⁴⁶ Department of Education (2005) Supplement to the Code of Practice on the Identification and Assessment of Special Educational Needs, Bangor: DE.

One year after the enactment of the Order, 67% of pupils with statements of SEN were being educated in mainstream schools; this compares with a figure of 63% immediately prior to the enactment of the Order and 56% in 2000.⁴⁴⁷ Despite increasing numbers, however, concern continues to be expressed at the quality of educational experiences received by children with disabilities within mainstream settings. In particular, there are concerns at the lack of resourcing, planning, training, participation and support. This has resulted in pupils with disabilities being placed in mainstream education settings that are ill prepared to meet their needs.⁴⁴⁸ Choosing appropriate educational provision is made increasingly difficult due to delays in diagnosis and assessment. There are no specific programmes in place which encourage people with disabilities to train as teachers.

There is a policy published on the DENI website on the collection of data on educational outcomes⁴⁴⁹. Information in relation to disability is collected, however it is not used or published either in the statistical releases or on the DENI website due to a lack of robustness. This is due to the measure being self reported by parents to the school and the absence of a validation mechanism. Outcomes from alternative education provision is also not included in the returns. There are also differences between a SEN designation and being a person being recorded as having a disability, for example out of 20805 post Primary Pupils in 2007/2008 recorded as Stage 1 to 5 SEN only 251 were recorded as having a disability.⁴⁵⁰ Data in relation to independent schools is not collected and the data from 'Special Schools' while being collected in a separate development stage project, is not published or included in the statistical return. The 'Special Schools' data uses measures which are validated by the schools. However, DENI Statistics and Research Branch do have an analysis of school leavers by their SEN stage which can be provided on request.⁴⁵¹

The Department of Education's (DENI) policy proposals for the 'Way Forward for Special Educational Needs and Inclusion' proposes a new framework which has emerged following a DE review of the current system. However, there are fears that the proposals will lead to greater uncertainty, reduce

⁴⁴⁷ Save the Children Northern Ireland and Children's Law Centre (2008) Northern Ireland NGO Alternative Report: Submission to the United Nations Committee on the Rights of the Child for Consideration during the Committee's Scrutiny of the UK Government Report. Save the Children and Children's Law Centre: Belfast.

⁴⁴⁸ Children with Disabilities Strategic Alliance (2009) Manifesto, Children in Northern Ireland/Disability Action; Northern Ireland Commissioner for Children and Young People (2008) Children's Rights: Rhetoric or Reality. A Review of Children's Rights in Northern Ireland 2007/08, NICCY: Belfast.

⁴⁴⁹ http://www.deni.gov.uk/school_leavers4.pdf.

⁴⁵⁰ DENI (2009) Equality Impact Assessment. The Way Forward for Special Educational Needs and Inclusion. Page 61, Table K

⁴⁵¹ Information from the Statistics and Research Branch, DENI September 2011

further the confidence of parents, and fail to effectively address the shortcomings of the current system. It is feared the proposals will erode the existing entitlement of children with disabilities to special educational needs provision. A consultation on the policy proposals concluded on 31 January 2010 with the final proposals yet to be published.

5.20.3.2. Transition services

“Education: equal access is not needs led but resource led. This starts the downward spiral in equality - Less chance of employment - live on benefits - no way out of the poverty trap! Nowadays you are scum being on benefit (media) Being on benefit and no chance of employment where does that place disabled people?”⁴⁵²

The Transitions Service assists young people to manage their transition into adulthood effectively by providing opportunities for young people with disabilities to visit colleges, training providers and employers and through group work or one-to-one sessions; enhancing personal development including confidence and self-esteem. The service empowers parents to help their young person through this process by providing information and support with home visits, telephone support and attending information evenings. The policy in relation to Transition services is complex and requires coordination between a diverse range of departments and agencies and as such the aspects of this policy are discussed throughout this report (see for example Article 27 Work and Employment). Concerns in relation to this matter made by focus group participants and through the conference questionnaire appear to be centred on this coordination aspect, but also relate to matters of choice and financial concerns. As previously reported a number of factors influence this reality including awareness and attitudes of employers, schools and also of families and the young people themselves. Structural issues such as accessibility both physical (for example transport and access to work placements) and insurance, impact greatly on choices for the young people and possible lines of development by the scheme coordinators.

‘forced down traditional routes – disabled people pigeon holed. Influenced into humanities’.⁴⁵³

⁴⁵² Comment from IMNI conference questionnaire (question 8)

⁴⁵³ Conclusion from a discussion group at the IMNI Conference Workshop on the 1/12/10 on the transition from education to employment.

5.20.4. Results from the questionnaire and the focus groups

The questionnaire results indicated that Education was rated as 4th in the key gap area between the UNCRPD and current policies (see paragraph question 12, 33.12 Appendix 1) by the group of disabled people (n=10) and the full respondent sample (n=28).

Respondents made the following comments which fall into two categories. Education was either an opportunity for awareness raising and empowerment or secondly that there was a link between poor education and poverty.

“Education and Employment - fewer qualifications leading to few / poor job opportunities”.⁴⁵⁴

“Day Centres - impossible to be catered for there as someone has to die to enable a young person to get a place-there is little stimulated activity to ensure lifelong learning-all the skills and independence they achieved at school is quickly lost within an environment in which the needs of the older residents are catered for and the mix of older and younger people doesn't quite work. Government need to be looking at alternative models of care-akin to those in Scandinavian countries, whereby another building for the young people is placed near to the school environment wherein they can continue the strive towards independent living within a supportive environment until 30-35 years. If we acknowledge that it takes these younger people many years to accomplish things that the rest of society take for granted why do we then assume that they will be able to cope with being thrown out of the only environment they have known to face the challenges of a hostile environment at the same time as young people who have studied for some years to acquire university places or have acquired the skills to moved into employment-it's hardly a level playing field. Unfortunately for many families caring for a young person with SLD's (severe learning difficulties) Post 19 transition becomes a time when the family as a whole descends into poverty as parents cannot person with SLD's (severe learning difficulties) Post 19 transition becomes a time when the family as a whole descends into poverty as parents cannot continue to work because of their caring responsibilities. It's a vicious circle”.⁴⁵⁵

⁴⁵⁴ Ibid

⁴⁵⁵ Response to the IMNI Conference questionnaire 1/12/10.

5.21. Article 25: Health

Article 25 - Health

States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- (a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- (b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons;
- (c) Provide these health services as close as possible to people's own communities, including in rural areas;
- (d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- (e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- (f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 25 recognises that persons with disabilities have the right to the enjoyment of the 'highest attainable standard of health without discrimination on the basis of disability'. The meaning of discrimination can be ascertained by reading Article 25 in light of Articles 2, 3 and 5. Article 25

requires States Parties to take 'all appropriate measures' to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. Such measures clearly include policies and programmes.

Article 25 elaborates further on the obligations of States Parties with respect to health. In particular, States Parties are required to:

- Provide persons with disabilities with the same **range** of free or affordable health care and programmes as provided to persons without disabilities;
- Provide persons with disabilities with the same **quality** of free or affordable health care and programmes as provided to persons without disabilities;
- Provide persons with disabilities with the same **standard** of free or affordable health care and programmes as provided to persons without disabilities.

As such, there should be policies and programmes in place aimed at the realisation of these obligations. States Parties are required to pay particular attention in respect of each of these obligations to the area of (i) sexual and reproductive health and (ii) population-based public health programmes.

States Parties are also required to provide:

- Health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention; and
- Services designed to minimise and prevent further disabilities, including among children and older persons.

These obligations require health services to be responsive to the needs of people with a range of 'disabilities'. The term 'disabilities' should be read in light of Article 1 which states that persons with disabilities **include** (but are not restricted to) "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". Early identification and intervention policies and programmes should be in place, while services designed to minimise and prevent further disabilities should be designed to take account of children and older persons.

'These' health services, that is, health services which are needed by persons with disabilities specifically because of their disabilities, should be provided 'as close as possible to people's own communities, **including in rural areas**'.

Article 25(c) requires health professionals to provide care to people with disabilities that is of the same quality as the care provided to others. Such care should be provided on the basis of free and informed consent. In so doing, States Parties are required to raise awareness of the (i) human rights (ii) dignity (iii) autonomy and (iv) needs of persons with disabilities. This

should be done through training and dissemination of ethical standards for both public and private health care. Policies and programmes should be in place reflecting these obligations.

Article 25(e) requires States Parties to **prohibit** discrimination against persons with disabilities in the provision of health insurance and life insurance where life insurance is permitted by national law.

States Parties are also required to **prevent** discriminatory denial of the following on the basis of disability:

- health care
- health services
- food
- fluids

Whilst Article 25 does not stipulate the means through which discriminatory denial of health care or services, and food or fluids is to be achieved, the nature of the obligation requires States Parties to take positive steps to prevent such discriminatory denial from occurring. This can be achieved partly through policies and programmes.

The obligation to prohibit and prevent discrimination should be read in light of Articles 2, 3 and 5.

5.21.1. Consideration of other UN human rights treaties

The right to health is recognised in numerous international instruments, most notably in Article 12 of the Covenant on Economic, Social and Cultural Rights.

The Committee on Economic, Social and Cultural Rights has stipulated that the “realisation of the right to health may be pursued through numerous, complementary approaches, such as the formulation of health policies, or the implementation of health programmes... or the adoption of specific legal instruments.”⁴⁵⁶

The right to health is not to be understood as a right to be healthy. The right to health contains both freedoms and entitlements. The freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health.⁴⁵⁷

⁴⁵⁶ Committee on Economic, Social and Cultural Rights (2000) General Comment 14: The right to the highest attainable standard of health, at para 1

⁴⁵⁷ Committee on Economic, Social and Cultural Rights (2000) Para 8.

The Committee on Economic, Social and Cultural Rights interprets the right to health as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health. A further important aspect is the participation of the population in all health-related decision-making at the community, national and international levels.⁴⁵⁸

In addition, health facilities, goods and services as well as **programmes** should be:

- Available in sufficient quantity within the State Party;
- Accessible to everyone without discrimination (including physically accessible and economically accessible). Accessibility also includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality;
- Acceptability: All health facilities, goods, services and programmes must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned;
- Quality: As well as being culturally acceptable, health facilities, goods, services and programmes must also be scientifically and medically appropriate and of good quality. This requires, inter alia, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation.

The right to health, like all human rights, imposes three types or levels of obligations on States Parties: the obligations to respect, protect and fulfil. In turn, the obligation to fulfil contains obligations to facilitate, provide and promote. The obligation to respect requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health. The obligation to protect requires States to take measures that prevent third parties from interfering with Article 12 guarantees. Finally, the obligation to fulfil requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional and other measures, including **policies and programmes**, towards the full realisation of the right to health.

⁴⁵⁸ Committee on Economic, Social and Cultural Rights (2000) Para 11.

The Committee on Economic, Social and Cultural Rights has also stipulated that violations of the obligation to fulfil occur through the failure of States Parties to take all necessary steps to ensure the realisation of the right to health, including the absence of, or failure to adopt or implement particular policies and programmes designed to ensure the right to health for everyone; insufficient expenditure or misallocation of public resources which results in the non-enjoyment of the right to health by individuals or groups, particularly the vulnerable or marginalised; the failure to monitor the realisation of the right to health at the national level, for example by identifying right to health indicators and benchmarks; the failure to take measures to reduce the inequitable distribution of health facilities, goods and services; the failure to adopt a gender-sensitive approach to health; and so on.⁴⁵⁹

In respect of early identification, the Committee on the Rights of the Child has highlighted that early identification requires high awareness among health professionals, parents, teachers as well as other professionals working with children. They should be able to identify the earliest signs of disability and make the appropriate referrals for diagnosis and management. The Committee recommends that State Parties establish systems of early identification and early intervention as part of their health services, together with birth registration and procedures for following the progress of children identified with disabilities at an early age. Services should be both community- and home-based, and easy to access. Furthermore, links should be established between early intervention services, pre-schools and schools to facilitate the smooth transition of the child. Following identification, the systems in place must be capable of early intervention including treatment and rehabilitation providing all necessary devices that enable children with disabilities to achieve their full functional capacity in terms of mobility, hearing aids, visual aids, and prosthetics among others. It should also be emphasised that these provisions should be offered free of cost, whenever possible, and the process of acquiring such services should be efficient and simple avoiding long waits and bureaucracies.⁴⁶⁰

5.21.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 25 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the UNCRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

⁴⁵⁹ Committee on Economic, Social and Cultural Rights (2000) Para 52.

⁴⁶⁰ Committee on the Rights of the Child 43rd session (2006) Paras 56-57.

- Measures that protect against discrimination and ensure that persons with disabilities have the same access to quality health services, including in the area of sexual and reproductive health;
- Measures taken to ensure that persons with disabilities have access to disability-related health rehabilitation in their community freely and without financial cost;
- Health services, early detection and intervention programmes, as appropriate, to prevent and minimise the emergence of secondary disabilities, paying attention to children, women and the elderly, including in rural areas;
- Measures to ensure that general public health campaigns are accessible for persons with disabilities;
- Measures put in place to train doctors and other health professionals on the rights of persons with disabilities, including in rural areas;
- Measures to ensure that any health treatment is provided to persons with disabilities on the basis of their free and informed consent;
- Measures that ensure protection against discrimination in the access to health insurance and other insurance, when these are required by law.
- Measures taken to insure that sanitation facilities are not simply available, but fully accessible;
- Measures taken to increase awareness and information in various accessible formats, including in Braille, for HIV/AIDS and malaria prevention.

5.21.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

To ensure compliance with Article 25 of the UNCRPD, CERMI has highlighted in its shadow report on **Spain** that there is a need for special proposals concerning the right to reproductive health especially for women with disabilities, for rare diseases to be considered a public health issue and for the regulation of informed consent to be formulated and implemented.⁴⁶¹

⁴⁶¹ CERMI, 'Human Rights and Disability: Spain Report 2009', 27 May 2010, at 38.

5.21.4. Key policies and programmes in Northern Ireland relevant to Article 25

Access to proper health and social care is critical for ensuring an independent quality of life for disabled people. Article 25 recognises that persons with disabilities have the right to the enjoyment of the 'highest attainable standard of health without discrimination on the basis of disability'. The meaning of discrimination can be ascertained by reading Article 25 in light of Articles 2, 3 and 5. Article 25 requires States Parties to take 'all appropriate measures' to ensure access for persons with disabilities to health services that are gender sensitive, including health-related rehabilitation. Such measures clearly include policies and programmes.

The Department of Health, Social Services and Public Safety has recently published its Draft Equality Action Plan⁴⁶² which has highlighted action areas in relation to the care provided to disabled people. Some of these issues have been dealt with in other Articles, for example, people with sensory impairment facing difficulties in accessing information about Health and Social Care service or domestic and sexual violence. However, the report highlights other areas of concern and these are listed below.

5.21.4.1. Mental capacity

The DHSSPS recognise that those lacking mental capacity to make decisions for them-selves do not have their rights protected in law. New legislation is proposed - the Mental Capacity (Health, Welfare and Finance) Act which may take to 2013 to enact. In conjunction with the new law, there will be new policies and programmes required, including a Code of Practice and training for staff who have a key role in implementing the provisions of the Bill. They also recognise that people with disabilities/lacking capacity are one of the groups most at risk of not having their views heard in decisions affecting their health or well-being. The DHSSPS proposed the development of a regional policy on the commissioning and provision of advocacy services (which includes for people with mental health problems, learning disabilities, physical and sensory disabilities and dementia). The content of this policy is not yet publicly available and thus cannot be assessed, but it is a key policy with respect to the implementation of the CRPD in Northern Ireland. This policy is expected to be finalised and released in spring 2011. The policy will pave the way for the introduction of the new statutory right to an independent advocate which is included in the proposed Mental Capacity (Health, Welfare and Finance) Bill. Full implementation will also be dependent on the continued funding of advocacy services in the new Comprehensive Spending Review and additional funding associated with

⁴⁶² <http://www.dhsspsni.gov.uk/disability-action-plan-26june.pdf>

the Bill. Currently the Bamford Review of Mental Health and Learning Disability Services has concluded that there is clear evidence of inequalities in investment in this area compared with other regions in the UK.⁴⁶³

5.21.4.2. Health inequalities

The Disability Rights Commission (DRC) in 2006 carried out a formal investigation into the nature and causes of physical health inequalities experienced by people with mental health problems and/or learning difficulties in England and Wales; in particular it focused on what is being done and what should be done, to reduce these inequalities through primary care. The investigation involved a combination of consultation and evidence collecting techniques including questionnaires, focus groups, in-depth area studies, analyses of GP databases and statistics, a formal inquiry panel and road show events. The final report of the formal investigation was published by the DRC in September 2006.⁴⁶⁴

The report concluded that people with learning difficulties and/or mental health problems are more likely than other citizens 'to experience major illnesses, to develop them younger and die from them sooner'.

Some of the findings relating to physical health inequalities experienced by people with mental health problems and/or learning difficulties are listed below:

5.21.4.2.1. People with mental health disabilities

There are higher rates of ischemic heart disease, stroke, high blood pressure and diabetes among people with schizophrenia or bipolar disorder compared to the rest of the population.

People with schizophrenia are 90% more likely to get bowel cancer and 42% more likely to get breast cancer (women only).

31% of people with schizophrenia and chronic heart disease (CHD) are diagnosed under 55, compared to 18% of others with CHD; these figures are 41% and 30% respectively for diabetes.

After five years, 28% of people who have had a stroke and have schizophrenia have died, as have 19% of people with bipolar disorder, compared with 12% of people with no serious mental health problems.

⁴⁶³ <http://www.dhsspsni.gov.uk/bamford.htm/>

⁴⁶⁴ www.drc.org.uk/healthinvestigation

5.21.4.2.2. People with learning disabilities

People with learning difficulties have higher rates of respiratory disease at 19.8% than the remaining population (15.5%).

People with learning disabilities are more likely to be obese. The rate of obesity in all those with their body mass index (BMI) recorded was 28.3% in people with a learning disability, as compared to 20.4% for the remaining population.

The British Medical Association examined health inequalities in 2007⁴⁶⁵ and concluded that, "While more comprehensive and robust data are needed on health inequalities, there is evidence that disabled people experience various inequalities in health outcomes when compared to non-disabled people and that access to healthcare services is often inequitable. Access barriers can also be significant and include inappropriate communication and information systems which can prevent disabled people from knowing what services are available, how to access them or how to use them effectively. Poor physical access or poorly designed buildings and facilities can also create significant barriers for people who have mobility impairments".⁴⁶⁶

The BMA report recommended increased participation of disabled people and their representatives with healthcare professionals, Awareness raising (including disability champions), recognition in provision that disabled people are not a homogeneous group, training of staff, better monitoring and impact assessments to ensure compliance with disability legislation and better planning for the provision of services to disabled people.

Mencap produced a report; 'Death by indifference' (2007)⁴⁶⁷ in which it highlighted the widespread ignorance and indifference throughout the health care services towards people with a learning disability resulting in poorer healthcare which they stated amounted to institutional discrimination. They presented the stories of 6 people whom they alleged died unnecessarily.

Within Northern Ireland, inequalities in access to health care are widely recognised. See for example the RNID report 'A Simple Cure'⁴⁶⁸ and a joint RNID/RNIB/BDA report "Is it my Turn Yet? Access to GP practices in Northern Ireland for people who are deaf, hard of hearing, blind or partially sighted

⁴⁶⁵ BMA (2007). Disability equality within health care: The role of healthcare professionals, BMA: UK

⁴⁶⁶ Ibid (Page 1)

⁴⁶⁷ Mencap (2007) Death by indifference: Mencap: UK

⁴⁶⁸ <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/research-reports.aspx>

within Northern Ireland.⁴⁶⁹ These conclusions are also reflected in the DHSSPS 2011 draft Disability Action Plan⁴⁷⁰

The RNID⁴⁷¹ Report "A Simple Cure"⁴⁷² found that:

- 35% of deaf and hard of hearing people had experienced difficulty communicating with their GP or nurse and 32% found it difficult to explain their health problems to their GP;
- 35% of deaf and hard of hearing people had been left unclear about their condition because of communication problems with their GP or nurse;
- 33% of sign language users were either unsure about medication instructions, or had taken too much or too little of a medication because of a communication problem.

There are also problems with access to GP practices in Northern Ireland for people who are deaf, hard of hearing, blind or partially sighted. The joint RNID/RNIB/BDA report on access to GP practices⁴⁷³ shows that there are concerns about accessibility. The findings of this Report include:

- Half of the GP practices have yet to provide any training to staff about deaf, visual, or general disability awareness – and only 15% of GPs have had any disability training;
- Although 50% of those GP practices which responded have induction loops in their waiting rooms, only 16% of these have loops in consulting rooms, suggesting hearing aid users may face greater difficulties communicating when with a GP or practice nurse;
- A majority (65%) of GP practices have visual display boards: a positive development for people who are deaf or hard of hearing - but is enough being done to assist people who are blind or partially sighted to get to their appointments and consulting rooms?

An ECNI investigation has also identified that people with learning disabilities face serious challenges such as poor communication from healthcare staff, a lack of understanding of their health needs, and a lack of user friendly written information in accessible formats.⁴⁷⁴

⁴⁶⁹ <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/research-reports.aspx>

⁴⁷⁰ http://www.dhsspsni.gov.uk/draft_equality_action_plan.doc

⁴⁷¹ The Royal National Institute for Deaf People (RNID) changed its name to Action on Hearing Loss in June 2011

⁴⁷² <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/research-reports.aspx>

⁴⁷³ RNID/RNIB/BMA (2010) "Is it my Turn Yet? Access to GP practices in Northern Ireland for people who are deaf, hard of hearing, blind or partially sighted within Northern Ireland." RNID: Belfast <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/research-reports.aspx>

⁴⁷⁴ ECNI (2008). Section 75 Formal Investigation into the Accessibility of Health Information for People with a Learning Disability 2006-2008., ECNI: Belfast.

5.21.5. Results from the questionnaire and the focus groups

Health was not rated highly as a gap area between the requirements of the UNCRPD and current policies in Northern Ireland in the conference questionnaire.

Comments from participants in the workshop did however comment that adequate health care is required but the primary issues were information and staff attitudes.

“Lack of awareness of the part of public bodies as to what the support needs are to ensure that people with disability can participate fully e.g. accessible formats, easy read documents, making sure that loop systems are available, that they are working and that staff know how to work them - lack of leadership that directs staff to make sure that information sent out by health staff is in accessible formats e.g. appointment letters can be read by people with visual impairment, that people with hearing impairment aren’t expected to phone in to confirm or change an appointment. - Need to look at feedback and complaints processes to ensure that people with disabilities have confidence in the system to give their views. - Need to look at how we recruit people for posts within HSC, how we support people to work as volunteers or on work placements. - HSC organisations need to monitor who are on our boards, - HSC organisations need to monitor who are on our boards, partnerships, user groups etc - and identify how many are people with disability. - Need to develop effective staff training”⁴⁷⁵.

The attitudes of staff in the Health service was commented on by a focus group participant who thought that “staff treated (the) condition not the person”⁴⁷⁶.

⁴⁷⁵ Comment made by a respondent to the IMNI Conference Questionnaire 1/12/10

⁴⁷⁶ Comments by a participant at the Thematic Focus Group on the 19/1/11

5.22. Article 26: Habilitation and rehabilitation

Article 26 - Habilitation and rehabilitation

- 1 States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
 - (a) Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
 - (b) Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
- 2 States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
- 3 States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 26 requires States Parties to take 'effective and appropriate measures' to enable persons with disabilities to attain and maintain:

- maximum independence;
- full physical, mental, social and vocational ability; and
- full inclusion and participation in all aspects of life.

This is clearly a wide ranging and deep obligation in the emphasis it places upon **maximum** independence and **full** ability and inclusion. In order to achieve this end States Parties must 'organise, strengthen and extend'

comprehensive habilitation and rehabilitation services and programmes and these must particularly be in the areas of:

- health;
- employment;
- education; and
- social services.

Articles 26 (1) (a) and (b) detail the manner in which these services and programmes must be provided. They must:

- begin at the earliest possible stage;
- be based on the multi-disciplinary assessment of individual needs and strengths;
- support participation and inclusion in the community and all aspects of society;
- be 'voluntary', i.e. not be forced on persons with disabilities; and
- be available to persons with disabilities as close as possible to their own communities, including in rural areas.

Articles 26 (2) and (3) contain obligations to promote:

- the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services; and
- the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

'Promotional' activities may include the adoption of policies and the development and implementation of programmes by State Parties, but there is not a requirement for such.

5.22.1. Consideration of other UN human rights treaties

The Committee on the Rights of the Child, in the context of children, has stipulated that the importance of community-based assistance and rehabilitation strategies should be emphasised when providing health services for children with disabilities.⁴⁷⁷

⁴⁷⁷ Committee on the Rights of the Child 43rd session (2006) Para 52

5.22.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 26 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- General habilitation and rehabilitation programmes for persons with disabilities, in the areas of health, employment, education and social services, including early intervention, peer support, and the availability of these services and programmes in rural areas;
- Measures taken to ensure that participation in habilitation and rehabilitation services and programmes is voluntary;
- The promotion of initial and continuous training for professionals and staff working in habilitation and rehabilitation programmes;
- Measures taken for the promotion, availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation;
- Measures taken for the promotion of international cooperation in the exchange of assistive technologies in particular with Third World countries.

5.22.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

Australia offer policies which cover rehabilitation in employment, rehabilitation in healthcare and exchange of assistive technologies. The Disability Employment Services provide specialist assistance to job seekers with disabilities, injuries or health conditions, and provide vocational rehabilitation as required to help persons with disabilities find and retain safe and sustainable employment in the open labour market. These service providers may assist job seekers to understand, compensate for and manage their injury or disability by building work capacity and developing work strategies to avoid re-injury. Additionally, each Australian jurisdiction has its own workers' compensation scheme directed at enabling injured workers to

return to work. Australia has provided support to Australian NGOs working in international development for provision of assistive devices and infrastructure to assist persons with disabilities using the World Health Organisation's 'Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings'.⁴⁷⁸

5.22.4. Key policies and programmes in Northern Ireland relevant to Article 26

This article seeks to ensure that disabled people attain and maintain as independent lives as possible. As discussed above the programs that are required include awareness training programs for staff, adaptive technologies, and the full participation of disabled people and supportive programs in health, employment, education and social services. This is not a restrictive list and the measures to ensure the habilitation and rehabilitation of disabled people as included in all Articles of the UNCRPD. It includes all the measures to ensure the full participation in life, including the support to be able to volunteer (Article 5) to the availability of assistive technologies under Article 9. The policies and programs in Northern Ireland are discussed in all the sections of this report.

The PSI report commented that it is essential that clear pathways should be established⁴⁷⁹ and that adequate training and funding is provided. Some good examples of this are available, for example the General Medical Council set up the Curriculum for the Foundation Years, a two-year generic training programme pursued by all newly-qualified doctors in the UK, which includes awareness of disability legislation. However as previously discussed (for example, see Article 25 Health) much remains to be done to ensure the equal access to the services disabled people require to ensure their full integration into society.

5.22.5. Results from the questionnaire and the focus groups

Independence and the habilitation and rehabilitation measures required to achieve it, was a notable theme in the results from the questionnaire and the focus groups.

Respondents reported that they were unclear as to the success of the opportunities currently being offered to disabled people.

⁴⁷⁸ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 157-161.

⁴⁷⁹ OFMdFM (2009) Report of the Promoting Social Inclusion Working Group on Disability: OFMdFM: Belfast

“Sadly the status quo seems to be that there is what there is, politicians are sympathetic but lack the drive to challenge the system and put proper structures and opportunities in place for young people with severe learning disabilities (to live) a fully inclusive and independent life”⁴⁸⁰.

Respondents also reported difficulties with the process of rehabilitation.

5.22.6. General comment

As reported in Article 19, independent living and the habilitation and rehabilitation services and systems required to achieve this is the subject of a current inquiry by the Parliamentary Joint Committee on Human Rights⁴⁸¹. While a more detailed exploration of the area would be advantageous, it is considered outside the scope and timeframe of the present study.

5.23. Article 27: Work and employment

Article 27 - Work and employment

- 1 States Parties recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:
 - (a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;

⁴⁸⁰ Comment made by a Carer in the IMNI Conference questionnaire 1/12/10.

⁴⁸¹ <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/right-of-disabled-people-to-independent-living-call-for-evidence/>

- (b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
 - (c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
 - (d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
 - (e) Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
 - (f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
 - (g) Employ persons with disabilities in the public sector;
 - (h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
 - (i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
 - (j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
 - (k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.
- 2 States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

In Article 27 States Parties recognise the right of persons with disabilities to work 'on an equal basis with others' and this is stated as explicitly including 'the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities'.

States Parties must both **safeguard** and **promote** the right to work for persons with disabilities, including those who acquire a disability in the course of employment. This must be done through 'appropriate steps, including through legislation'; these steps will clearly include appropriate policies and programmes. There are a diverse range of kinds of obligations within Article 27 which means that the policies and programmes required, and the basis on which they are required, is also diverse. In fulfilment of Article 27, States Parties must:

- 'prohibit';
- 'protect';
- 'ensure';
- 'employ'.
- 'enable'; and
- 'promote'.

Article 27 (1) (a) requires States Parties to **prohibit** discrimination on the basis of disability with regard to 'all' matters concerning all forms of employment. This provision of the Convention must be read in the light of Articles 3 (b), 3 (e) and 5. The breadth of application of 'all matters' is clarified through explicit inclusion of:

- conditions of recruitment;
- hiring and employment;
- continuance of employment;
- career advancement; and
- safe and healthy working conditions.

Article 27 (1) (b) requires States Parties to protect the rights of persons with disabilities, 'on an equal basis with others', to ensure:

- just and favourable conditions of work, including:
- equal opportunities and equal remuneration for work of equal value;
- safe and healthy working conditions;
- protection from harassment; and
- the redress of grievances.

The means of 'protection' may include the development and implementation of policies and programmes by States Parties. The obligations of Article 5 are also relevant here.

Article 27 (1) (c) and (i) require that States Parties **ensure**:

- that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others; and
- that reasonable accommodation is provided to persons with disabilities in the workplace.

Article 27 (1) (g) requires that States Parties **employ** persons with disabilities in the public sector.

Article 27 (1) (d) requires that States Parties **enable** persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training.

Article 27 (1) (e), (f), (h) (j) and (k) require that States Parties **promote**:

- employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;
- opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
- the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
- the acquisition by persons with disabilities of work experience in the open labour market;
- vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.

Article 27 (2) requires that States Parties ensure that 'persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour'. This requires that any policies or programmes in this area explicitly include consideration of the specific risks of being subjected to slavery and servitude persons with disabilities face. It also requires consideration of any 'special' situations of work which might apply only to persons with disabilities, such as some forms of 'sheltered employment', in the light of the general obligation and that policies be amended and programmes be discontinued as necessary in fulfilment of this article.

5.23.1. Consideration of other UN Human Rights Treaties

The right of everyone to work and employment is recognised in the Covenant on Economic, Social and Cultural Rights. The right to work in a general sense is proclaimed in Article 6. The individual dimension of the right to work is explicitly developed through the recognition in Article 7 of the

right of everyone to the enjoyment of just and favourable conditions of work, in particular the right to safe working conditions. The collective dimension of the right to work is addressed in Article 8, which enunciates the right of everyone to form trade unions and join the trade union of his/her choice.

The Committee on Economic, Social and Cultural Rights has stated that the exercise of the right to work in all its forms and at all levels requires the existence of the following interdependent and essential elements, implementation of which will depend on the conditions present in each State party:⁴⁸²

- (a) Availability. States Parties must have specialised services to assist and support individuals in order to enable them to identify and find available employment;
- (b) Accessibility. The labour market must be open to everyone under the jurisdiction of States Parties. Accessibility comprises three dimensions:
 - 1 Non-discrimination. Many measures, such as most strategies and programmes designed to eliminate employment-related discrimination, can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information.
 - 2 Physical accessibility.
 - 3 Accessibility includes the right to seek, obtain and impart information on the means of gaining access to employment through the establishment of data networks on the employment market at the local, regional, national and international levels.
- (c) Acceptability and quality. Protection of the right to work has several components, notably the right of the worker to just and favourable conditions of work, in particular to safe working conditions, the right to form trade unions and the right to freely choose and accept work.

The Committee on Economic, Social and Cultural Rights has stated that 'the "right of everyone to the opportunity to gain his living by work which he freely chooses or accepts" (Art. 6 (1)) is not realised where the only real opportunity open to disabled workers is to work in so-called "sheltered" facilities under sub-standard conditions. Arrangements whereby persons with a certain category of disability are effectively confined to certain occupations or to the production of certain goods may violate this right.⁴⁸³ Moreover governments should develop policies and programmes which promote

⁴⁸² Committee on Economic, Social and Cultural Rights (2005) General Comment 18: The right to work, Para 12

⁴⁸³ Committee on Economic, Social and Cultural Rights (1995) 'The rights of persons with disabilities' Para 21

and regulate flexible and alternative work arrangements that reasonably accommodate the needs of disabled workers.

The Committee on Economic, Social and Cultural Rights has stated that the “technical and vocational guidance and training programmes” (which are also referred to in Article 27 CRPD), required under Article 6 (2) of the CESCR should reflect the needs of all persons with disabilities, take place in integrated settings, and be planned and implemented with the full involvement of representatives of persons with disabilities.⁴⁸⁴

The Committee has also expanded on States Parties’ obligations to ‘respect, protect and fulfil’ the right to work more generally:⁴⁸⁵

- Obligations to **protect** the right to work include, inter alia, the duties of States Parties to adopt legislation or to take other measures ensuring equal access to work and training and to ensure that privatisation measures do not undermine workers’ rights. Specific measures to increase the flexibility of labour markets must not render work less stable or reduce the social protection of the worker. The obligation to protect the right to work includes the responsibility of States Parties to prohibit forced or compulsory labour by non-State actors.
- States Parties are obliged to **fulfil (provide)** the right to work when individuals or groups are unable, for reasons beyond their control, to realise that right themselves by the means at their disposal. This obligation includes, inter alia, the obligation to recognise the right to work in national legal systems and to adopt a national policy on the right to work as well as a detailed plan for its realisation. The right to work requires formulation and implementation by States Parties of an employment policy with a view to “stimulating economic growth and development, raising levels of living, meeting manpower requirements and overcoming unemployment and underemployment”⁴⁸⁶. It is in this context that effective measures to increase the resources allocated to reducing the unemployment rate, in particular among women, the disadvantaged and marginalised, should be taken by States Parties. Further, the obligation to fulfil (provide) the right to work includes the implementation by States Parties of plans to counter unemployment.
- The obligation to **fulfil (facilitate)** the right to work requires States Parties, inter alia, to take positive measures (including policies and programmes) to enable and assist individuals to enjoy the right to work and to implement technical and vocational education plans to facilitate access to employment.

⁴⁸⁴ Committee on Economic, Social and Cultural Rights (1995) Para 24.

⁴⁸⁵ Committee on Economic, Social and Cultural Rights (2005) General Comment 18: ‘The right to work’ Paras 25-28.

⁴⁸⁶ Ibid

- The obligation to **fulfil (promote)** the right to work requires States Parties to undertake, for example, educational and informational programmes to instil public awareness on the right to work.

5.23.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 27 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- The impact of targeted employment programmes and policies in place to achieve full and productive employment among persons with disabilities according to paragraphs 1 (a to g) of the Convention.
- The impact of measures to facilitate re-employment of persons with disabilities, who are made redundant as a result of privatisation, downsizing and economic restructuring of public and private enterprises according to paragraph 1 (e) of the Convention.
- Availability of technical and financial assistance for the provision of reasonable accommodations, including the promotion of the establishment of cooperatives and start ups in order to encourage entrepreneurialism.
- Affirmative and effective action measures for the employment of persons with disabilities in the regular labour market.
- Positive and effective action measures for the prevention of harassment of persons with disabilities in workplace.
- Accessibility of persons with disabilities to open employment and vocational training services, including those for the promotion of self employment.
- Information on existing significant differences in employment between men and women with disability and whether there are policies and legislation to cater for these differences in order to promote the advancement of women with disabilities.
- Identification of the most vulnerable groups among persons with disabilities (including by providing examples) and policies and legislation in place for their inclusion in the labour market.
- Measures taken for the promotion of the trade union rights of persons with disabilities.
- Measures taken to assure the retention and retraining of workers who suffer a workplace injury resulting in a disability preventing them from performing their previous tasks.

- Provide information on the work of persons with disabilities in the informal economy in the State Party, and the measures taken to enable them to move out of the informal economy, as well as on measures taken to ensure their access to basic services and social protection.
- Measures taken to ensure persons with disabilities who have technical and vocational skills are empowered with the support needed for their entry and re-entry to the labour market according to paragraph 1(k).
- Measures taken to ensure students with disabilities the same access to the general labour market.
- Measures taken to ensure various forms of work, such as work on location, telecommuting (off-site/at home) and subcontracting, and work opportunities offered by new communication technologies.

5.23.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

In **Australia**, the 'Wage Subsidy Scheme' provides a financial incentive for employers to employ workers with disabilities under normal labour market conditions. The 'National Mental Health and Disability Employment Strategy' aims to increase the employment of persons with disabilities, promote social inclusion and improve economic productivity. Highlights of the strategy include a 'Disability Support Pension Employment Incentive Pilot' and an 'Innovation Fund'.

The Employment Assistance Fund helps persons with disabilities and mental health conditions by providing financial assistance to purchase a range of work-related modifications and services for people who are currently working, as well as those who require assistance to find and prepare for work. In addition, there are policies in place in each State and territory to increase the employment of persons with disabilities in the public sector.⁴⁸⁷

The **Austrian** government has a range of measures for the occupational integration of people with disabilities. A 'Nationwide Labour Market Policy Programme for the Disabled' is drawn up biannually. This programme

⁴⁸⁷ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 162-171.

provides for individual funding (e.g. wage support and workplace adaptation) and project support and accompanying help (e.g. personal assistance, clearing, projects to help people obtain qualifications and employment projects). For registered people with disabilities there is increased protection against dismissal with the Disability Committee deciding whether a dismissal can take place. Additionally, the Ministry of Health takes a range of measures to involve people with disabilities through the 'Mentoring for People with Disabilities' project and ensuring that training is provided, interpreters are available and that the building is accessible.⁴⁸⁸

The 'National Employment Foundation' has been established in **Hungary** to promote the extension of employment, to improve the adaptation abilities of employees and job-seekers, to render services to employers as well as to improve the labour market chance of disadvantaged people and to promote their employment. Within this wage subsidies and mediators between employers and employees are made available.⁴⁸⁹

In its shadow report on Spain, CERMI has highlighted that setting specific quotas in access to employment for workers with disabilities is good practice with regard to Article 27 of the UNCRPD.⁴⁹⁰

5.23.4. Key policies and programmes in Northern Ireland relevant to Article 27

The ECNI 2008 Equality Awareness survey reported that knowledge of employment and disability rights had fallen from 2005.⁴⁹¹ Information from the focus groups in the present research reported that they had found discrimination was not overt but was due to the attitudes of employers / potential employers in relation to the capabilities of disabled persons and of the potential costs involved. This issue partly implies a gap with respect to action in relation to Article 8 on awareness raising.

The DDA positive action provisions are permissive only; there is no obligation on employers to adopt positive action measures. Positive discrimination⁴⁹² remains in general unlawful, but as it is not unlawful to discriminate against non-disabled people i.e. policies which exclude non-disabled people from applying may be lawful. Direct statistics in relation to the extent and/

⁴⁸⁸ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 41-44..

⁴⁸⁹ CRPD/C/HUN/1, 'Report to the Committee on the Rights of Persons with Disabilities: Hungary' (14 October 2010), at para 194-223.

⁴⁹⁰ CERMI, 'Human Rights and Disability: Spain Report 2009', 27 May 2010, at 40.

⁴⁹¹ <http://www.equalityni.org/archive/pdf/EASurveyPublicPresHandout230609.pdf>

⁴⁹² Positive discrimination is the automatic preference of applicants from particular groups in the recruitment process so that a less qualified applicant might be given a job over a better qualified rival.

or success of positive action duties are not available (information from Disability Action Employment Unit). It should be borne in mind that many do not declare themselves as being disabled when they have a disability. Employment rates in Northern Ireland for people of working age who have declared that they have a disability have fallen from 34.8% in quarter 3 2006 to 30.6% in quarter 3 2009 (from 34.8 to 30.6%).⁴⁹³

Articles 5 and 27 have been interpreted as empowering States to legitimise, where necessary, programmes of affirmative action and or effective quota regimes to ensure a fair and proportionate representation of persons with disabilities and persons without in the workforce. While there is some precedent in Northern Ireland the previous UK system contained in the 1944 and 1958 Disabled Persons (Employment) Acts introduced employment quota schemes, which required all employers to recruit at least three per cent of their workforce from (registered) disabled people (employers with fewer than 20 employees were exempt from this legislation). These schemes were generally ineffective and very few employers were prosecuted for ignoring the quotas. As a consequence, many disabled people did not register as disabled persons as registration was unlikely to improve their chances of gaining employment. Thus, official statistics are likely to undercount the number of unemployed disabled people.⁴⁹⁴

The Employment Unit of Disability Action has raised the issue that the specialist Disablement Employment advisors from the Disability Advisory Service (DAS part of DEL) have been replaced by more generic Employment Advisors (a move not mirrored in GB) under the Pathways to Work programme. This programme deals with the transition from incapacity benefit to work for people with short and long term illness (including disabled people) thus reducing the specialist help available to disabled people seeking work and their potential employers. There are Access to Work advisors who advise employers on access to work issues for disabled people however the level of service has been reduced.

5.23.5. Results from the questionnaire and the focus groups

The questionnaire revealed that respondents in the questionnaire reported that employment was the second most important area of public policy (after legislation) to enable persons with disabilities to fully participate in society (paragraph 3.9 Appendix 1, Q9). Respondents reported that it was the third most important policy gap between the requirements of the UNCRPD and current policy.

⁴⁹³ McQuaid R., Holywood E. and Canduela R., (2010) Employment Inequalities in an Economic Downturn, ECNI: Belfast

⁴⁹⁴ Stafford, B., Duffy, D. (2009) Review of evidence on the impact of economic downturn on disadvantaged groups, DWP Working Paper no. 68

Comments made by respondents in the questionnaire indicated barriers to employment including a lack of accessible transport, living in supported housing, transport and the 'benefit trap'.

"The benefit system needs looked at to reflect the standard of education disabled people are obtaining as the benefit trap can stop disabled people in certain circumstances going into employment".

Respondents reported concerns about prejudice in interviews; **"in terms of employment – (it) is perhaps that when people with a disability go for job interviews, how do they know for sure that they are not being discriminated against. There is potentially a financial and emotional cost in attempting to challenge issues such as this, especially in such a small community such as Northern Ireland"**, and keeping jobs when a disability develops: **"won't be taken on in employment – more likely to be off sick"**. A focus group respondent with a hidden disability reported not being believed that she was disabled and that she had to show her operation scar to her employer to prove it.

Unemployment was linked to poverty and negative attitudes about disabled people: **"this starts the downward spiral in equality - less chance of employment - live on benefits - no way out of the poverty trap! Nowadays you are scum being on benefit [media portrayal]. Being on benefit and no chance of employment. Where does that place disabled people?"**

However work was regarded by participants as meaningful; **"ensuring that young people with SLDs (severe learning disabilities) find meaningful and rewarding work experiences suited to their needs - it can be a very powerful learning experience for the workplace as a whole"**. However respondents commented that; **"people don't know about the (work) schemes"** and that work advertisements need to welcome disabled people.

5.24. Article 28: Adequate standard of living and social protection

Article 28 - Adequate standard of living and social protection

- 1 States Parties recognise the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability.
- 2 States Parties recognise the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realisation of this right, including measures:
 - (a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
 - (b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
 - (c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
 - (d) To ensure access by persons with disabilities to public housing programmes;
 - (e) To ensure equal access by persons with disabilities to retirement benefits and programmes.

Article 28 (1) recognises the right of persons with disabilities **and their families to an adequate standard of living** and commits States Parties to take 'appropriate steps' to both **safeguard** and **promote** the realization of this right without discrimination on the basis of disability. Whilst partly

recognising that persons with disabilities also enjoy an already recognized human right, Article 28 (1) also articulates an obligation on States Parties to ensure the realisation of this right for persons with disabilities in particular. The 'appropriate steps' will reasonably include a range of policies and programmes to cover both persons with disabilities and their families. Article 28 must be read in conjunction with the non-discrimination obligations of Articles 3 (b) and (5).

Article 28 (2) recognises the right of persons with disabilities to **social protection**, again requiring States to take 'appropriate steps' to safeguard and promote the realisation of this right. Article 28 (2) (a) to (e) lay out a range of measures which are to be included in the 'appropriate steps'. These measures are to ensure a range of outcomes, including:

- equal access to clean water;
- access to appropriate and affordable services, devices and other assistance for disability-related needs;
- access to social protection programmes;
- access to poverty reduction programmes;
- access by persons with disabilities and their families 'living in situations of poverty' to State assistance with disability related expenses (including training, counselling, financial assistance and respite care);
- access to public housing programmes;
- equal access to retirement benefits and programmes.

5.24.1. Consideration of other UN human rights treaties

Article 11 (1) of the Covenant on Economic, Social and Cultural Rights recognises the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions.

The Committee on Economic, Social and Cultural Rights has stipulated that the right to **housing** should not be interpreted in a narrow or restrictive sense which equates it with, for example, merely having a roof over one's head or viewing shelter exclusively as a commodity. Rather it should be seen as the right to live somewhere in security, peace and dignity.⁴⁹⁵

The Committee has identified a number of factors which should be taken into account in realisation of the right to adequate housing, a number of which require the development of policies and programmes.⁴⁹⁶

⁴⁹⁵ Committee on Economic, Social and Cultural Rights (1991) General Comment 4: The right to adequate housing, Para 7.

⁴⁹⁶ Committee on Economic, Social and Cultural Rights (1991), General Comment 4: The right to adequate housing, Para 8.

- Legal security of tenure.
- Availability of services, materials, facilities and infrastructure: An adequate house must contain certain facilities essential for health, security, comfort and nutrition. All beneficiaries of the right to adequate housing should have sustainable access to natural and common resources, safe drinking water, energy for cooking, heating and lighting, sanitation and washing facilities, means of food storage, refuse disposal, site drainage and emergency services.
- Affordability: Personal or household financial costs associated with housing should be at such a level that the attainment and satisfaction of other basic needs are not threatened or compromised. Steps should be taken by States Parties to ensure that the percentage of housing-related costs is, in general, commensurate with income levels. States Parties should establish housing subsidies for those unable to obtain affordable housing, as well as forms and levels of housing finance which adequately reflect housing needs.
- Habitability: Adequate housing must be habitable, in terms of providing the inhabitants with adequate space and protecting them from cold, damp, heat, rain, wind or other threats to health, structural hazards, and disease vectors. The physical safety of occupants must be guaranteed as well.
- Accessibility: Adequate housing must be accessible to those entitled to it. Disadvantaged groups must be accorded full and sustainable access to adequate housing resources. Thus, such disadvantaged groups as the elderly, children, the physically disabled, the terminally ill, HIV-positive individuals, persons with persistent medical problems, the mentally ill, victims of natural disasters, people living in disaster-prone areas and other groups should be ensured some degree of priority consideration in the housing sphere. Both housing law and policy should take fully into account the special housing needs of these groups.
- Location: Adequate housing must be in a location which allows access to employment options, health-care services, schools, childcare centres and other social facilities. This is true both in large cities and in rural areas where the temporal and financial costs of getting to and from the place of work can place excessive demands upon the budgets of poor households.
- Cultural Adequacy: The way housing is constructed, the building materials used and the policies supporting these must appropriately enable the expression of cultural identity and diversity of housing.

With respect to **clothing** in Article 28, the Committee on Economic, Social and Cultural Rights has recognised that “the right to adequate clothing also assumes a special significance in the context of persons with disabilities who

have particular clothing needs, so as to enable them to function fully and effectively in society.⁴⁹⁷

The Committee on Economic, Social and Cultural Rights has stated that the right to adequate food is realized when 'every man, woman and child, alone or in community with others, have physical and economic access at all times to adequate food or means for its procurement.'⁴⁹⁸ As such, the core content of the right to adequate food implies:

- The availability of food in a quantity and quality sufficient to satisfy the dietary needs of individuals, free from adverse substances, and acceptable within a given culture;
- The accessibility of such food in ways that are sustainable and that do not interfere with the enjoyment of other human rights.

In addition to economic accessibility, food must also be physically accessible; i.e. adequate food must be accessible to everyone, including physically vulnerable individuals, such as infants and young children, elderly people, the physically disabled, the terminally ill and persons with persistent medical problems.⁴⁹⁹

In this context, the obligation to **respect** existing access to adequate food requires States Parties not to take any measures that result in preventing such access. The obligation to **protect** requires measures (including policies and programmes) by the State to ensure that enterprises or individuals do not deprive individuals of their access to adequate food. The obligation to **fulfil (facilitate)** means the State must proactively engage in activities (including policies and programmes) intended to strengthen people's access to and utilisation of resources and means to ensure their livelihood, including food security. Finally, whenever an individual or group is unable, for reasons beyond their control, to enjoy the right to adequate food by the means at their disposal, States have the obligation to **fulfil (provide)** that right directly.⁵⁰⁰

5.24.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 28 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the

⁴⁹⁷ Committee on Economic, Social and Cultural Rights (1995), General Comment 4: The right to adequate housing, at Para 33.

⁴⁹⁸ Committee on Economic, Social and Cultural Rights (1999) General Comment 12: The right to adequate food, at Para 8.

⁴⁹⁹ Committee on Economic, Social and Cultural Rights (1999) General Comment 12: The right to adequate food, at Para 13.

⁵⁰⁰ Committee on Economic, Social and Cultural Rights (1999) General Comment 12: The right to adequate food, at Para 15.

Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to ensure availability and access by persons with disabilities to clean water, adequate food, clothing and housing and provide examples;
- Measures taken to ensure access by persons with disabilities to services, devices and other appropriate assistance at affordable prices, including the availability of programmes that cover disability related extra financial costs;
- Measures taken to ensure access by persons with disabilities, in particular women and girls and older persons with disability, to social protection programmes and poverty reduction programmes;
- Measures towards public housing programmes and retirement benefits and programmes for persons with disabilities;
- Measures taken to recognise the connection between poverty and disability.

5.24.3. Key policies and programmes in Northern Ireland relevant to Article 28

Research by the Joseph Rowntree Foundation and the New Policy Institute has indicated that disabled adults are now more likely to live in poverty than either children or older people.⁵⁰¹ Research has also indicated that, globally, around 43% of people with disabilities can be categorised as ‘extremely poor’.⁵⁰² In the UK it is estimated that disabled adults are twice as likely to live in poverty as non-disabled adults. Indeed, there is a close association across the lifecycle between disability and poverty. On almost any recognised indicator of poverty, disabled people are found to be significantly over-represented. Disability poverty is not just about low income but relates to lack of opportunity and other barriers, and the additional costs associated with disability.⁵⁰³

Government measures of poverty are based on an ‘income only’ method. This measure uses a ‘poverty line’ which is set as a proportion of median income. Currently, an income threshold of less than 60% of national median ‘equivalised’ household income is used to track poverty rates. Equivalisation refers to the process by which household income is adjusted to account for variation in household size and composition. Income is divided by scales which vary according to the number of adults and the number and age of

⁵⁰¹ Palmer, G., MacInnes, T. and Kenway, P. (2006) *Monitoring Poverty and Social Exclusion*, Joseph Rowntree Foundation and New Policy Institute: York.

⁵⁰² Inclusion International (1999), *Fact Sheet on Poverty and Disability*.

⁵⁰³ Parckar, G. (2008) *Disability Poverty in the UK*, Leonard Cheshire: London.

dependants in the household.⁵⁰⁴ This process of equalisation does not account for household variation by disability

In Northern Ireland, the Family Resources Survey has been used to calculate poverty levels. This survey defines disability as 'a long-term illness, disability or infirmity that limits the activity of the individual in some way'. However, no adjustment is made to disposable household income to take into account of any additional costs that may be incurred due to disability. At a household level almost two out of every five (37%) Northern Ireland households include at least one person with a disability.⁵⁰⁵ The Monitoring Poverty and Social Exclusion in Northern Ireland study (2006), using the Family Resources Survey found that over the period 2002/2003 and 2004/2005, just over a third of those in income poverty in Northern Ireland are living in households with at least one disabled adult.⁵⁰⁶ The study also showed that disabled adults of working age are one and a half times as likely as people without disabilities of working age to be in income poverty (25%, around 10% higher than people without disabilities in Northern Ireland).

In 2003, the Poverty and Social Exclusion in Northern Ireland study, using a consensual measure of poverty, found that 56% of households comprising one or more disabled persons are in poverty compared to 29% of households without disabled persons.⁵⁰⁷ The consensual measure of poverty uses a combination of income and deprivation to define poverty wherein a sample of the general public are asked to decide what the basic necessities of life are.

The report also found that there may have been some underreporting of disability by survey respondents in poor households. The overall conclusion however is that disabled people are nearly twice as likely to be in poverty as non-disabled people.

In their report on Child and Family poverty (2006), McLaughlin and Monteith, using the PSENI consensual measure of poverty, found that approximately 3 in 5 (57%) disabled children are poor compared to approximately 2 in 5 (37%) children without disabilities. Approximately 3 in 5 (59%) of children living with a chronically ill or disabled parent are poor.⁵⁰⁸ The report

⁵⁰⁴ Save the Children (2007) A 2020 Vision: Ending Child Poverty in Northern Ireland, p.59.

⁵⁰⁵ Northern Ireland Statistics and Research Agency (2007) The Prevalence of Disability and Activity Limitations amongst adults and children living in private households in Northern Ireland, NISRA: Belfast.

⁵⁰⁶ Kenway, P., MacInnes, T., Kelly, A. and Palmer, G. (2006) Monitoring poverty and social exclusion in Northern Ireland, Joseph Rowntree Foundation: York.

⁵⁰⁷ Hillyard, P., Kelly, G., McLaughlin, E., Patios, D. and Tomlinson, M. (2003) Bare Necessities: Poverty and Social Exclusion in Northern Ireland, Democratic Dialogue: Belfast.

⁵⁰⁸ McLaughlin, E. and Monteith, M. (2006) Child and Family Poverty in Northern Ireland, Equality and Social Need Division, OFMDFM: Belfast

indicated that families with disabled children are disproportionately likely to be in poverty and the presence of a disabled parent increases the risk of poverty even further.

Household or family income is the usual starting point for the analysis of poverty. However, the rate at which individuals can translate income into a standard of living varies. Thus, the same level of income represents different standards of living for different people.⁵⁰⁹ Many disabled people face additional costs of living in order to achieve the same basic standard of living as people without disabilities.

The Every Disabled Child Matters campaign (2007) has highlighted that the rate of Disability Living Allowance (DLA) in recent years has been rising at a rate of around 2.5%, barely in line with inflation. The Disability Alliance has estimated that an increase in DLA in the region of 30%-50% would come closer to meeting the true additional costs of disability. Ultimately then, the way in which DLA is currently included in poverty measures masks the true levels of disability poverty.

While the tax and benefit system does acknowledge that people with disabilities incur additional costs, for example through provision of DLA, the system fails to recognise the **true** costs of disability.⁵¹⁰ Poverty measures which are based on income only figures (and which counts DLA as income) do not give a full picture of the poverty levels experienced by people with disabilities because they do not take into account the true extent of additional expenditure.

These additional costs arise from the barriers disabled people face such as having to pay for taxis because public transport is inaccessible; having to pay for particular adaptations, aids or technologies; or having to pay for social care support.

Research conducted by Leonard Cheshire estimates that disabled people face extra costs which amount, on average, to approximately an extra quarter above normal expenditure. The magnitude and composition of extra costs are likely to vary by type and severity of impairment as well as the stage of the life-cycle and living circumstances of the individual concerned.⁵¹¹ There have been relatively few attempts to measure these additional costs. As research has highlighted, "Rigorous analysis of poverty and disability

⁵⁰⁹ Zaidi, A. and Burchardt, T. (2003) Comparing incomes when needs differ: Equivalisation for the extra costs of disability in the UK. CASE Paper 64: London.

⁵¹⁰ Zaidi, A. and Burchardt, T. (2003) Comparing incomes when needs differ: Equivalisation for the extra costs of disability in the UK. CASE Paper 64: London, McLaughlin, E. and Monteith, M. (2006) Child and Family Poverty in Northern Ireland, Equality and Social Need Division, OFMDFM: Belfast, Parckar, G (2008) Disability Poverty in the UK, Leonard Cheshire: London.

⁵¹¹ Ibid

requires ... adaptations to be made in the calculation of poverty rates...the result is that poverty risk rates for households with disabled children and for a disabled parent may be higher than reported" (McLaughlin and Monteith 2006: para 2.13).

Zaidi and Burchardt (2003) have estimated that, when the extra costs of disability are factored in, over 50% of disabled people live on less than 60% of median national income, as opposed to the unadjusted figure of around 30%. This clearly indicates that current poverty rates for disabled people are grossly underestimated. Similarly, income only measures of poverty do not consider indicators and experiences of poverty relating to health, education, employment, housing and access to services; that is, poverty of opportunity, access and expectation.

The correlation between disability and poverty is well established. However, in order to make realistic judgements about the numbers of disabled people living in poverty, it is vital to recognise the additional costs that many disabled people face. Both the Leonard Cheshire report and research conducted by Zaidi and Burchardt (2003) argue that there is a strong need for the development of robust disability-adjusted poverty statistics which take account of the extra costs of disability. The Leonard Cheshire report makes recommendations both for indicators for monitoring disability poverty and a series of social policy recommendations for challenging it.

Proposed indicators in the Leonard Cheshire report relate to a range of areas, including areas where data is not currently collected - for example:

- Savings;
- Employment rates;
- Types of work;
- Benefit take-up;
- Accommodation;
- Educational attainment;
- Quality of life;
- Access to services.

Given the lack of research on disability poverty in Northern Ireland, there is a need for a clear and focused strategy in this regard, including the development of an appropriate measure of disability poverty and of policies and programmes to prevent it?

5.24.4. Results from the questionnaire and the focus groups

Questionnaire respondents reported that poverty was an issue for disabled people and that there was a link to employment and being unable to participate in society,

“if we don’t work to support ourselves and our families we can be excluded from many aspects of society as we do not have the resources to enable us to participate. Disabled people are more likely to live in poverty than anyone else in society”⁵¹².

5.25. Article 29: Participation in political and public life

Article 29 - Participation in political and public life

States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

- (a) Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:
 - (i) Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
 - (ii) Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;
 - (iii) Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;

⁵¹² Comment from a respondent to the IMNI Conference questionnaire 1/12/10

- (b) Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
 - (i) Participation in non-governmental organisations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;
 - (ii) Forming and joining organisations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

With Article 29 States Parties guarantee political rights to persons with disabilities and the opportunity to enjoy them 'on an equal basis with others'. This is to be achieved through both ensuring rights and promoting an environment.

Article 29 (a) requires States Parties to ensure that persons with disabilities can effectively participate in political and public life 'on an equal basis with others'. This includes ensuring the right and opportunity for persons with disabilities to vote and be elected by:

- ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;
- protecting the right to vote by secret ballot without intimidation;
- protecting the right to stand for elections;
- protecting the right to effectively hold office;
- protecting the right to perform all public functions at all levels of government; and
- by facilitating the use of assistive and new technologies where appropriate.

Article 29 (b) requires that States Parties actively promote an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs and encourage their participation. This is to be done without discrimination and 'on an equal basis with others'. The means for achieving this are to include:

- participation in non-governmental organisations and associations;
- participation in the activities and administration of political parties;
- forming and joining organisations of persons with disabilities.

Throughout Article 29 there is an emphasis not only on ‘full’ participation, but on ‘effective’ participation. The obligation to ensure the latter is clearly significant in assessing the adequacy of the range of policies and programmes which aim at delivering on its obligations.

5.25.1. Consideration of other UN human rights treaties

The right to vote and to participate in public life is set out in Article 25 of the International Covenant on Civil and Political Rights. The Human Rights Committee has stated that States Parties must take effective measures to ensure that all persons entitled to vote are able to exercise that right. Where registration of voters is required, it should be facilitated and obstacles to such registration should not be imposed.⁵¹³ Positive measures, including policies and programmes, should be taken to overcome specific difficulties, such as illiteracy, language barriers, poverty, or ‘impediments to freedom of movement’ which prevent persons entitled to vote from exercising their rights effectively. Information and materials about voting should be available in minority languages.⁵¹⁴ The Committee has also stated that assistance provided to people with disabilities should be independent and electors should be fully informed of these guarantees.⁵¹⁵

The Committee stipulates that the criteria and processes for appointment, promotion, suspension and dismissal must be objective and reasonable. Affirmative measures may be taken in appropriate cases to ensure that there is equal access to public service for all citizens. Finally, the Committee has stated that in order to ensure the full enjoyment of this right as articulated in Article 25 ICCPR, the free communication of information and ideas about public and political issues between citizens, candidates and elected representatives is essential.⁵¹⁶

5.25.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 29 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures to guarantee to persons with disabilities, in particular persons with mental or intellectual disability, political rights, including, if it is the case, existing limitations and actions taken to overcome them;

⁵¹³ Human Rights Committee (1996) General Comment No.25: The right to participate in public affairs, voting rights and the right of equal access to public service, at Para 11.

⁵¹⁴ Human Rights Committee (1996) Para 12.

⁵¹⁵ Human Rights Committee (1996) Para 20.

⁵¹⁶ Human Rights Committee (1996) Para 25.

- Measures taken to ensure the right to vote of all persons with disabilities, on their own or to be assisted by a person of their choice;
- Measures taken to ensure the full accessibility of the voting procedures, facilities and materials;
- Indicators measuring the full enjoyment of the right to participate in the political and public life of persons with disabilities;
- Support provided, if any, to persons with disabilities for the establishment and maintenance of organisations to represent their rights and interests at local, regional and national level.

5.25.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

The **Australian** Electoral Commission provides voters with a disability with a range of options to vote. For example, in the 2010 Federal Election telephone voting was available to voters who are blind or have low vision, to provide the voter with a secret vote. A checklist has been created to ensure that polling stations are accessible for people with disabilities. Furthermore, to assist voters with disabilities a range of information and services have been developed. This included making election information available in Braille, large print and e-text, and making voters aware of how to cast an early vote if they could not attend a polling station. People with disabilities are also able to stand for election and hold public office. In addition, the Australian government provides funding to a number of national disability peak bodies who consult with persons with disabilities and draw on the resources of member organisations to provide the Australian government with the perspective of people with disabilities.⁵¹⁷

In **Austria** voters who are unable to attend the polling station have the option of being visited by a 'flying election commission' or casting a postal vote. It is possible for voting cards to be sent automatically before every election. With regard to representation, disabled persons representatives have been established to represent the interests of disabled workers in

⁵¹⁷ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 178-184.

companies. Furthermore, organisations specialising in disability are relied upon to represent the interests of people with disabilities in government.⁵¹⁸

In its shadow report on **Tunisia**, the Atlas Council have proposed that persons with mental disabilities could have their rights under Article 29 of the UNCRPD respected by allowing such persons the right to vote with the aid of a third party if required.⁵¹⁹

5.25.4. Key policies and programmes in Northern Ireland relevant to Article 29

Whilst focused on this article, the concerns expressed by the majority of respondents from the Questionnaire study and the focus groups was in relation to participation in its broadest sense from being able to participate in government lobbying groups, to being able to participate fully in court proceedings but the central area of concern was the right to participate in deciding the policies and programmes which affected their lives. Article 29 is reinforced by the fundamental principle of “full and effective participation and inclusion in society”, provided for in Article 3(c) UNCRPD, and by the general obligation “to closely consult with and actively involve persons with disabilities” in all aspects of decision-making, provided for in Article 4(3) UNCRPD. “Read in conjunction with Articles 3 and 4, Article 29 provides one of the clearest expressions in international human rights law of the right to participate in decision-making”⁵²⁰.

“Ask first – ‘the person with the disability knows what the disabled person needs’”⁵²¹.

Policy in this regard is contained in part in the ‘Disability Duties⁵²²’ under Section 49 of the Disability Discrimination Act 1995⁵²³ in which public authorities are required to have due regard to (i.e. to take into account) the need to promote positive attitudes towards disabled people and encourage the participation of disabled people in public life when exercising their functions. Further advice is also contained in good practice guides issued by the various organs of the State and an example of these is the

⁵¹⁸ CRPD/C/AUT/1, ‘Report to the Committee on the Rights of Persons with Disabilities: Austria’ (2 November 2010), at 45-46.

⁵¹⁹ Atlas Council (2010), ‘Redefining Disability’, Atlas Council: Tunisia.

⁵²⁰ The European Foundation Centre (EFC), (2010) Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, , VC/2008/1214.

⁵²¹ Comment from Participant of the scoping focus group on the 10.1.2011Austria’ (2 November 2010), at 45-46.

⁵²² ECNI (2007) A Guide for Public Authorities - Promoting positive attitudes towards disabled people and encouraging the participation of disabled people in public life. ECNI: Belfast.

⁵²³ As amended by Article 5 of the Disability Discrimination (Northern Ireland) Order 2006

excellent practical guide to policy making issued by the OFMdFM⁵²⁴, which encourages policy makers to actively involve front line staff and service users early in the policy making process. The guidance issued by the ECNI⁵²⁵ in relation to the disability duties and other government guidelines would, if fully implemented, negate many of the concerns expressed by people with disabilities and their representatives, however the lack of substantive enforcement powers reduces its effectiveness and the positive practical impact of the lives of disabled people.

Under the Disability duties, public authorities must submit a Disability Action Plan⁵²⁶ and must report on progress on and must submit a report on their progress to the ECNI on an annual basis (annual progress report). The Disability Plans must be for more than a year and the ECNI Guide to the Disability Duties recommends that public authorities ensure the time period for the plan coincides with their corporate planning cycle (e.g. 3-4years). Whilst there is a legal requirement for the Equality Commission to approve Equality Schemes under Section 75, there is no legal requirement on the ECNI to approve Disability Action Plans under the Disability Duties.⁵²⁷ The Disability Action Plans must be reviewed at the same time as a public authority reviews its Equality Scheme under section 75 The ECNI has limited formal powers of enforcement regarding the Disability Duties with the options of reporting non compliance to the NI Assembly and Judicial review. The researchers in the ECNI 2009 study commented that the lack of formal enforcement powers which are essentially only able to name and shame public authorities in the report to the assembly, has impacted on the ability to “effect meaningful action where a public authority has not taken steps to comply with its duties”.⁵²⁸

The 2009 study for the ECNI also noted that out of the 21 public authorities assessed, 8 provided evidence they had consulted or involved disabled people in the production of their Disability Action Plans. However, 13 public authorities provided little evidence of meaningful consultation in terms of the activities undertaken, by reporting in detail on these activities and the outcomes of these activities. None of the 21 public authorities assessed in the research reported having systems in place to monitor and evaluate their Disability Action Plan as a whole. The report noted a lack of accessible formats to the plans which it suggested creates barriers to participation. The

⁵²⁴ OFMdFM, A Practical Guide to Policy Making, <http://www.ofmdfmi.gov.uk/policylink>

⁵²⁵ ECNI (2007). A Guide for Public Authorities- Promoting positive attitudes towards disabled people and encouraging the participation of disabled people in public life, ECNI : Belfast

⁵²⁶ A Disability Action plan is a plan of how a Public Authority proposes to fulfill their Disability Duties in relation to its functions

⁵²⁷ ECNI (2009): Effectiveness of the Disability Duties, Review Report, ECNI: Belfast

⁵²⁸ McIlWhan R, Roger S and Bridge S. (2009) Evaluating the effectiveness of the Disability Discrimination (NI) Order 2006 Duties. ECNI: Belfast

report also noted a misunderstanding amongst public authorities regarding the definition of public life with some public authorities defining public life positions as public appointments rather than the definition contained in the Commission's guide. The Commission's Guide defines public life as including "government public appointments; the House of Lords; public bodies' focus or working groups; community associations or fora; community police liaison committees; neighbourhood watch committees; citizens' panels; local strategic partnerships; school boards of Governors, school councils; youth councils; user groups for a service provided by a public authority".⁵²⁹ The report further comments that, "the Commission's analysis of plans has also noted a predominant focus by public authorities' on public appointments rather than a broader focus on participation at the local, national and regional level as outlined in the Guide".⁵³⁰

The ECNI study also commented that compliance with the disability duties is independent of a public authority's compliance with other disability-related legislation such as the DDA and with Section 75 and reported that while many of the measures would comply with requirements under the Section 75 or the Disability Discrimination Act they did not directly contribute to promoting positive attitudes towards disabled people or encouraging the participation of disabled people in public life, and therefore do not meet the requirement of the disability duties.

An examination for this study of a sample of public authorities' Disability Plans revealed that only a few of the current Disability Action Plans (February 2011) have addressed the issues specifically raised in the UNCRPD. For example, the current actions in the DENI Draft Disability Action Plan 2010 - 2013 make only one reference to the UNCRPD in directing policy makers to consider the implications of human rights policies - including the United Nations Convention on the Rights of Persons with Disabilities when completing the Equality and Human Rights Screening form. As reported earlier there are a number of specific requirements in relation to education contained in the UNCRPD notably in relation to Awareness Raising (Article 8) and the provision (Article 24-4) to employ teachers who are qualified in sign language and / or Braille and to train professionals and staff. However, it is noted that in action point 15 in the DENI Disability Action Plan, that the Department will review arrangements for communication between schools and deaf or hard of hearing parents by March 2011, although no specific plans or targets are indicated. It was also noted that the Department will consult with staff on the formation of a Disability Focus group from 2010/11 onwards.

⁵²⁹ ECNI (2007). A Guide for Public Authorities - Promoting positive attitudes towards disabled people and encouraging the participation of disabled people in public life. ECNI: Belfast.

⁵³⁰ McIlWhan R, Roger S and Bridge S. (2009) Evaluating the effectiveness of the Disability Discrimination (NI) Order 2006 Duties. ECNI: Belfast.

The results from the ECNI study suggest that greater coordination and agreed standards for the 'Disability Duties' process is required and evidence from the children's sector (see Article 7) suggests that the establishment of a consultation network or a Commissioner's office with the necessary skills could provide a conduit for the participation process for government.

5.25.4.1. Participation in the activities and administration of political parties

One in five of the electorate has a disability; based on Electoral Office figures for the total electorate.⁵³¹ That means there are 239,144 voters in Northern Ireland who may require information in accessible formats.

A review by Disability Action of the accessibility of political party information for people with disabilities for the Westminster Elections May 2010⁵³² found problems with the typeface, layout and language used in Party election leaflets, for example 71% did not have advice on how to get information in other formats and many leaflets provided information on the types of ID that could be used at the polling station. However, most of these lists did not include the full list of IDs, for example, they did not include the use of a Blind Person's Smartpass.

In relation to election party broadcasts none of the programmes considered had subtitles, none used sign language and not all had contact details so that people could contact the party for further information.

Disability Action made a number of requests to political parties for large print and audio copies of their manifestos. Only three of the five parties contacted were able to send information in the format requested. Of these only one would be deemed to be of a suitable quality and format for someone who is blind or visually impaired. One party directed the person making their enquiry to a large print copy of their manifesto available on their website and should be commended for this. In relation to Easy Read from researching party websites and printed materials there is no indication that any information was provided in Easy Read.

Enquiries were made with the parties to explore the barriers they faced in making information more accessible. In most cases the biggest barrier was the lack of knowledge and skills within the party on how to make information accessible.

Cost was also seen as one of the barriers to political parties. A number of parties raised the issue of allowed costs per elector and how this would

⁵³¹ http://www.eoni.org.uk/august_2010_electorate_by_ward.pdf.

⁵³² Disability Action (2010). Accessibility of Political Party Information for People with Disabilities for the Westminster Elections May 2010, Disability Action:UK

impact on the cost of producing accessible information. A suggestion was made that candidates should be allowed additional expenditure to allow for costs in providing accessible information.

It is clear from the audit of materials, the requests made to political parties for alternative formats, and the focus groups, that many people with disabilities were not able to access information from political parties in a format that suited their needs in the run up to the General Election of 2010. This finding is supported by research from the European Foundation Centre (EFC) which reported that even though most EU Member States have adopted legislative provisions in order to ensure that persons with disabilities can participate in voting procedures, these are not enough to ensure full and effective participation of all persons with disabilities. Indicative case-studies show that while States ensure accessibility to polling stations and ballots, general information about the elections is not provided in alternative formats (e.g. Braille or Easy Read formats).⁵³³

A recent Mencap survey showed that 90% of the voting population cannot understand phrases used in political literature.⁵³⁴ The research was undertaken as part of the Mencap 'Get My Vote' Campaign. The campaign aims to empower people with a learning disability to vote by persuading political parties to make their manifestos and information easier to understand. Many people commented that they did not understand what political parties stood for because of the difficult language they used.

The study concluded that to ensure communication is accessible, political parties must develop strict design guidelines to ensure that all the communications they produce are based on the principle of accessibility and produced at the same time as other material. Better training should be provided to those with communication responsibilities and engagement should be undertaken with local disability organisations and disabled people to ensure that the guidelines they produce will meet the needs of people with disabilities.

The study also commented that political parties must consider how they engage with people with disabilities, not just as possible voters but as constituents, party members and as employees. It recommended that all parties should review their policies and procedures to ensure that they are effectively engaging people with disabilities in the democratic process.

⁵³³ The European Foundation Centre (2010). Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, 'The European Foundation Centre (EFC), VC/2008/1214.

⁵³⁴ <http://www.mencap.org.uk/news.asp?id=12817&pageno=4&year=&menuId=91>.

“Parties – don’t want to know you- only when they are seeking votes”⁵³⁵.

“No disability outreach person in political parties”⁵³⁶.

“Increase participation of disabled people in political parties and contact from political parties with disabled people and groups”⁵³⁷.

“In relation to political life what support should be in place: a car/driver, accessible transport, access (overall), accessible information / scribe etc?”⁵³⁸.

Disability Action has also undertaken a study into the accessibility of the voting process for people with disabilities in Northern Ireland over a number of years.⁵³⁹ While difficulties remain with access to information, physical accessibility has greatly improved from the last survey in 2009. For example, those respondents reporting that there was no parking for disabled people had improved from 45% in 2009 to 18.6% in 2010 and respondents reporting that there was no low level booth had improved from 20.9% in 2009 to 4.9% in 2010.

The Electoral Commission has set out its strategy for implementing its disability duties under the DDA in its 2008 Disability Equality Scheme⁵⁴⁰ and comments that since The Electoral Administration Act 2006 it is now enabled to set performance standards and to require election officers and local authorities to provide information against the performance standards. However the duties of the State under the UNCRPD are not referred to in the document and the Disability Action study in 2010 suggests that much work in relation to the access to information to enable the participation in the political process and the access of disabled people into political parties is still required.

5.25.4.2. Participation under Article 29(b)

Another potential policy gap concerns the requirements of Article 29 (b) which comment that the State should promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

⁵³⁵ Comments from participants at the second Thematic Focus Group on the 26th January 2011 (Participation In Political And Public Life).

⁵³⁶ Ibid

⁵³⁷ Ibid

⁵³⁸ Ibid

⁵³⁹ Disability Action (2010). Polls Apart Survey 2010, Disability Action: UK

⁵⁴⁰ <http://www.electoralcommission.org.uk/search?isadvanced=false&query=disability+plan&form=simple&daat=on>

- participation in non-governmental organisations and associations;
- participation in the activities and administration of political parties; (see paragraph above)
- forming and joining organisations of persons with disabilities.

While there are some good examples of participation schemes in Northern Ireland, for example the Count us in Project⁵⁴¹ which seeks to increase political participation, there is a great deal of anecdotal evidence that for many people with disabilities, participation is reduced or eliminated due to factors such as the absence of interpreters or care assistants or the non payment of costs, for example transport, when involved in participation in non-governmental organisations and associations and forming and joining organisations of persons with disabilities such as lobbying groups and social clubs.

“Problems in the access to transport to get to the venue / setup – layout in the venue. For example is it on the ground floor? Are there toilets? Are there wider automatic doors, a loop system and interpreters. Is information available in Easy Read, Braille, or large print, is there someone to scribe for you?”⁵⁴².

This study has not found any other evaluation study, other than the ECNI study reported above, on the effectiveness of participation schemes with disabled people. The European Foundation Centre (EFC) study⁵⁴³ also commented that while the majority of the EU Member States have created consultative disability forums in order to ensure the participation of persons with disabilities in public life, little information is available in relation to the effectiveness of such forums.

As previously reported in Article 21 the RNID highlighted that one of the barriers to participation of deaf and hard of hearing people was that there are only 11 fully qualified, registered sign language interpreters in Northern Ireland and 7 junior trainee interpreters⁵⁴⁴ and that this has the potential to exclude access for people who are deaf.

According to RNID (2009) one in ten respondents to its annual survey (n = 6,608) had not received the communication support they needed or were offered the wrong type of support. This finding highlights that service

⁵⁴¹ <http://www.electoralcommission.org.uk/news-and-media/public-awareness-campaigns/partnership-grants/grants-awarded/disability-action-northern-ireland>.

⁵⁴² Comment from a participant at the second Thematic Focus Group on the 26th January 2011 (Participation In Political And Public Life)

⁵⁴³ The European Foundation Centre (2010). Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, 'The European Foundation Centre (EFC), VC/2008/1214

⁵⁴⁴ Correspondence from RNID (Action for Hearing Loss) to Project team November 2010

providers should be more aware of the need to provide communication support and more aware of the different types of support that are available⁵⁴⁵.

It was noted during this study that in order to facilitate the full participation of disabled people with diverse requirements in the focus groups that considerable financial outlay was required to pay for such matters as transport, room adaptation, communication aids, the payment of care assistants, interpreters and transport costs. Considerable organisation was also required with respect to transport, the arrangement of accessible formats and interpreters who notably, in the case of sign interpreters, were not always available. Participants' medical appointments and general health also excluded some people from participating fully at short notice. All these factors would suggest that unless suitable finance and trained, experienced staff are available the full participation of disabled people may not be achievable without specialist assistance.

As previously reported research suggests the establishment of a Participation Network, similar to that funded by the OFMdfM for Children and Young Persons, to act as an expert interface between Government and disabled people may be effective in increasing the meaningful participation of and consultation with disabled people. This may also be helpful in complying with Article 29 (a) which requires States Parties to ensure that persons with disabilities can effectively participate in political and public life 'on an equal basis with others'.

This was highlighted in the results from the focus group who commented;

"Disabled forum would be useful - somewhere [where] the government could consult"⁵⁴⁶.

"A Disability Commissioner and advisory forum could give us the voice we lack at this time"⁵⁴⁷.

"Assembly / Departments (to) have a forum of disabled people or a participation network that they can come to"⁵⁴⁸.

Participants from the focus group also highlighted that they believed that they were being consulted (if at all) rather than participating at an early stage in the process and they recommend the adoption of an ASK FIRST standard as adopted by the children's sector (see Article 7). The involvement of disabled people at an early stage of policy development was a theme in the PSI report and should be adopted by government and coordinated by the OFMdfM.

⁵⁴⁵ RNID (2009) Annual Report.

⁵⁴⁶ Comments from participants in the Scoping Focus Group held on the 14/1/11

⁵⁴⁷ Ibid

⁵⁴⁸ Comment from a participant in the Thematic Focus Group on the 19/1/11

There is an obligation to actively promote an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs without discrimination and on an equal basis with others, and encourage their participation in public affairs. There does appear to be some policy, notable the DEL funding for Sign Language Interpreters and Translink transport policies. However a significant cultural change following awareness raising is required to make this positive environment a reality.

5.25.5. Results from the questionnaire and the focus groups

Evidence from the conference questionnaire, the conference workshop and the scoping focus groups clearly identified the participation of disabled people in political and public life as a main area of interest.

The results from the questionnaire suggested that respondents considered the lack of participation as a key barrier to inclusion in society and as a gap between the requirements of the UNCRPD and current policies and programmes (see Appendix 1). This was confirmed at the workshop and at the scoping focus group at which participation was clearly identified as a key area. The literature review and interviews with key stakeholders confirmed this conclusion and a thematic focus group was held to examine the area and suggest some solutions.

Participants at this focus group on the 26/1/11 commented that they believed they were merely consulted with (if at all) rather than participating in the formulation of policies and programmes at an early stage.

“Can get people to “listen” but they don’t actually hear”.

“Consultation rather than participation”.

The focus group participants proposed the establishment of a participant network as an interface between disabled people and government to ensure that they were “ASK(ed) FIRST”. They commented that there appeared to be a lack of action currently coming from Government in consultation exercises and that they would take a more active role if there was evidence of this. They recommended that policy makers consider arrangements when holding participation sessions to allow more time and access and to fully support participants, including any costs.

They proposed more proactive engagement from political parties to ensure they were included in political life and decision making. They recommended that political parties should have Disability Champions separate from Equality Officers.

Participants believed that access to information and data including statistics was vital to ensure full participation. Participants recommended awareness raising especially amongst decision makers and politicians but also with disabled people and the public.

A participant further recommended, **“training and capacity building of disabled people especially with regard to lobbying skills and how to access information”** in order to fully participate in society.

5.25.6. Key Area

The participation of people with disabilities in political and public life was consistently an area of concern raised by disabled people and their representatives in the ECNI conference questionnaire results and the focus groups. It is considered an important cross cutting measure which has significant impact on the majority of people with a disability in influencing the services and choices they have.

5.26. Article 30: Participation in cultural life, recreation, leisure and sport

Article 30 - Participation in cultural life, recreation, leisure and sport

- 1 States Parties recognise the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:
 - (a) Enjoy access to cultural materials in accessible formats;
 - (b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
 - (c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.
- 2 States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.
- 3 States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.

- 4 Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.
- 5 With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:
 - (a) To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
 - (b) To ensure that persons with disabilities have an opportunity to organise, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
 - (c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
 - (d) To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
 - (e) To ensure that persons with disabilities have access to services from those involved in the organisation of recreational, tourism, leisure and sporting activities.

In Article 30 (1) States Parties recognise the right of persons with disabilities to take part in cultural life on 'an equal basis with others' and commits them to taking 'all appropriate measures' accordingly. The aims of these measures are articulated in Article 30 (1) (a) to (c). States Parties must ensure that persons with disabilities:

- enjoy access to cultural materials in accessible formats;
- enjoy access to television programmes, films, theatre and other cultural activities in accessible formats; and
- enjoy access to places for cultural performances or services and 'as far as possible' to monuments and sites of national cultural importance.

Article 30 (2) to (4) impose additional obligations in this area and Article 30 (5) (a) to (d) addresses recreational, leisure and sporting activities. Article 30 (2) requires States Parties to take 'appropriate measures' to enable persons with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential. Article 30 (3) requires States Parties to ensure that laws relating to intellectual property rights do not constitute an 'unreasonable or discriminatory' barrier to persons with disabilities accessing cultural materials. This should clearly be read in conjunction with Articles 1 and 5. According to Article 30 (4), persons with disabilities are entitled, 'on an equal basis with others', to recognition and support of their specific cultural and linguistic identity. It includes explicit reference to sign languages and deaf culture. The policies and programmes necessary for the realisation of this right are distinct from those which essentially constitute non-discrimination and equality measures, including reasonable accommodation. Recognition of and support for a culture and identity are distinct from disability discrimination and equality measures. Article 30 (5) aims to enable persons with disabilities to participate 'on an equal basis with others' in recreational, leisure and sporting activities. To this end, States Parties are required to take 'appropriate measures' which are articulated in Article 30 (5) (a) to (d). The measures aim to:

- encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
- ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on 'an equal basis with others', of appropriate instruction, training and resources;
- ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system; and
- ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

5.26.1. Consideration of other UN human rights treaties

In its most recent General Comment the Committee on Economic, Social and Cultural Rights has elaborated upon 'the right to take part in cultural life', highlighting a number of necessary conditions for the full realisation of everyone to take part in cultural life on the basis of equality and non-discrimination.⁵⁴⁹

⁵⁴⁹ Committee on Economic, Social and Cultural Rights (2009) General Comment 21: 'Right of everyone to take part in cultural life', Para 16.

- Availability - the presence of cultural goods and services that are open for everyone to enjoy and benefit from;
- Accessibility - effective and concrete opportunities for individuals and communities to enjoy culture fully within physical and financial reach for all in both urban and rural areas without discrimination. It is also essential that 'access for persons with disabilities is provided and facilitated'. Accessibility also includes the right of everyone to seek, receive and share information on all manifestations of culture in the language of the person's choice, and the access of communities to means of expression and dissemination;
- Acceptability - policies and programmes should be formulated and implemented in such a way as to be acceptable to the individuals and communities involved. In this regard, consultations should be held with the individuals and communities concerned;
- Adaptability - refers to the flexibility and relevance of strategies, policies and programmes adopted in any area of cultural life;
- Appropriateness - refers to the realisation of a specific human right in a way that is pertinent and suitable.

The Committee, in its General Comment on Persons with Disabilities, has stated that the right to full participation in cultural and recreational life for persons with disabilities further requires that communication barriers be eliminated to the greatest extent possible. In order to facilitate the equal participation in cultural life of persons with disabilities, governments should inform and educate the general public about disability. Similarly, the general public should be educated to accept that persons with disabilities have as much right as any other person to make use of restaurants, hotels, recreation centres and cultural venues.⁵⁵⁰

The Convention on the Rights of the Child stipulates in Article 31 the right of the child to recreation and cultural activities appropriate to the age of the child. The Committee on the Rights of the Child has asserted that the attainment of full inclusion of children with disabilities in society is realised when children are given the opportunity, places, and time to play with each other (children with disabilities and no disabilities).⁵⁵¹ The Committee has also stipulated that "because of the physical demands of the sport, children with disabilities will often need to have exclusive games and activities where they can compete fairly and safely. It must be emphasized though that when such exclusive events take place, the media must play its role responsibly by giving the same attention as it does to sports for children with no disabilities."⁵⁵²

⁵⁵⁰ Committee on Economic, Social and Cultural Rights (1995), Paras 37-38.

⁵⁵¹ Committee on the Rights of the Child 43rd session (2006) General Comment 9 'The rights of children with disabilities', at Para 70.

⁵⁵² Committee on the Rights of the Child 43rd session (2006), General Comment 9 'The rights of children with disabilities' Para 71.

5.26.2. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 30 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of UNCRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to recognise and promote the right of persons with disabilities to take part on an equal basis with others in cultural life, including opportunities to develop and utilise their creative, artistic and intellectual potential;
- Measures taken to ensure that cultural, leisure, tourism and sporting facilities are accessible to persons with disabilities, taking into account children with disabilities, including through the conditional use of public procurement and public funding;
- Measures taken to ensure that intellectual property laws do not become a barrier for persons with disabilities in accessing cultural materials, including participation in relevant international efforts;
- Measures taken to promote deaf culture;
- Measures taken to support the participation of persons with disabilities in sports, including elimination of discriminatory and differentiated treatment of persons with disabilities in the awarding of prizes and medals;

Measures taken to ensure that children with disabilities have access on an equal basis with all other children to participation in play, recreation, leisure and sporting facilities, including those made within the school system.

5.26.3. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

In **Austria** a range of sporting, recreational and cultural facilities and locations have been adapted and financed to create barrier-free access to persons with disabilities. Sports associations receive subsidies to accommodate persons with disabilities in their events. Tourism related staff

are trained to deal with the individual needs of people with disabilities and special packages have been developed.⁵⁵³

In **Hungary**, the 'Regional Operative Programme' prescribes in all cases concerning tourism an obligatory condition that facilities should be freely accessible. The national tourism database contains information - voluntarily supplied by the service providers - on accessible tourism facilities.

In its shadow report as the 'independent mechanism' for **Spain**, CERMI have highlighted that there is a lack of compliance with accessibility guidelines set to make cultural, recreational, leisure and sporting facilities barrier-free for people with disabilities. Spanish night clubs and cinemas have been particularly non-compliant. This highlights the need for mechanisms to be created which ensure compliance.⁵⁵⁴

5.26.4. Key policies and programmes in Northern Ireland relevant to Article 30

Many of the requirements of Article 30 relate to access issues and these are considered under Article 9 on Accessibility.

Article 30 (4) requires that persons with disabilities "shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture." The issue of the equal treatment of deaf culture within Northern Ireland is of longstanding concern. The significance of this right was covered in the extensive recommendations of the Report of the Working Group on Culture and Identity and Language of the Bill of Rights Forum.⁵⁵⁵ As effective recognition of the distinct cultural identity of sign language users in fulfilment of Article 30 impacts potentially on all policies and programmes, it has not been possible to document the key policies and programmes which are most relevant given the scope of this project.

5.26.5. Results from the questionnaire and the focus groups

There were no relevant comments in the questionnaire or focus group in relation to this article. Comments made in relation to access to venues and the availability of information is discussed in Article 9.

⁵⁵³ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 48

⁵⁵⁴ CERMI, 'Human Rights and Disability: Spain Report 2009', 27 May 2010, at 41-43.

⁵⁵⁵ See http://www.billofrightsforum.org/cil_final_report.pdf

Article 31: Statistics and data collection

Article 31 - Statistics and data collection

- 1 States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:
 - (a) Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;
 - (b) Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.
- 2 The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.
- 3 States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.

Article 31 is clearly an article of cross-cutting impact on the implementation of the Convention and its full requirements in terms of policies and programmes are only determinable in the light of the requirements of all of the substantive articles of the Convention. It requires that statistics and data are collected with reference to:

- the formulation of policies to give effect to the Convention;
- the implementation of policies to give effect to the Convention;
- the identification of barriers faced by persons with disabilities in exercising their rights; and
- addressing the barriers faced by persons with disabilities in exercising their rights.

The obligation of Article 31(1) is clear in that it requires States Parties to collect appropriate information to enable them to formulate and implement policies to give effect to the present Convention. This requires that

government agencies have policies on the collection of relevant information, where 'relevance' is established by the engagement of an article of the Convention. Article 31 places information gathering as a direct obligation on States Parties, rather than such activities simply being the implied means of meeting the obligations contained in other articles.

In order to meet this obligation, any particular State Party must clearly identify what information is relevant to its ability to 'give effect to' the Convention and collect that information accordingly. It is also explicitly envisaged, in both the text of the article and its title, that this information will include 'statistical and research data'. Article 31(1) (a) and (b) lay out the standards which must be adhered to in the collection of the information. Article 31(2) imposes an obligation with respect to the use of the information which States Parties are required to gather under article 31(1). Namely, that it will be used to assess implementation as well as in the development of policies as required by 31(1).

Article 31(2) further requires that information collected 'be disaggregated, as appropriate' which clearly means that information gathered under 31 (1) be of a nature to allow it to be disaggregated. Article 31 (2) imposes a second use for the information, namely, that it be used 'to identify and address the barriers faced by persons with disabilities in exercising their rights'. It is noteworthy that it does not State 'their rights under the present Convention' and the obligation should thus be taken broadly to include other rights, or possibly minimally, other human rights. The nature of the policies and programmes required by Article 31(1) with respect to statistics and data collection are clarified by the uses intended for such information which are spelt out in Article 31(2).

Article 31(3) spells out an obligation to disseminate the information and ensure it is accessible to persons with disabilities and others. Who precisely comes under 'others' is only determinable in particular State Parties in the light of the object and purpose of the Convention.

5.27.1. Comments from the Committee on the Rights of Persons with Disabilities

With respect to Article 31 in the Guidelines on treaty-specific document to be submitted by States Parties under Article 35, paragraph 1, of the CRPD, the Committee on the Rights of Persons with Disabilities requires that the State report should cover:

- Measures taken to collect disaggregated appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention respecting human rights and fundamental freedoms, ethics, legal safeguards, data protection, confidentiality and privacy;

- The dissemination of these statistics and measures to ensure their accessibility by persons with disabilities;
- Measures taken to ensure the full participation of persons with disabilities in the process of data collection and research.

5.27.2. Reports to the Committee on the Rights of Persons with Disabilities

Some content from reports submitted to the Committee on the Rights of Persons with Disabilities are considered here as illustrative of the kinds of policies and programmes which are being implemented by other States Parties. These reports were examined to assist in the interpretation of the Convention, but they have proven of limited value in this respect. They should not be taken as examples of good practice; nor are they necessarily required by the Convention, since there are multiple ways in which the obligations of any particular Article might be met.

Australia has introduced a number of measures to bring it into line with Article 31 of the UNCRPD. All Australian governments annually provide data for a 'Disability Services National Minimum Data Set' on government-funded disability services. The Dataset provides nationally comparable data about 'National Disability Agreement' funded services. The 'Survey of Disabilities and Carers' provides disability prevalence rates for Australia and is the main source of data used to assist government departments and community groups in the development of relevant policies to meet the needs of Australians with a disability. Furthermore, all publications, spreadsheets and Census data on the 'Australian Bureau of Statistics' website are available free to any member of the public with internet access.⁵⁵⁶

The **Austrian** government launched its first 'Report on People with Disabilities' in 2008 and intends to carry out similar research and publish findings every few years. This is additional to annual social reports which contain statistical data on people with disabilities. Furthermore, research carried out concerning employment and long-term care has all contained sections dealing with people with disabilities.⁵⁵⁷

In its shadow report on Spain, CERMI draws attention to the 'Survey on Disability, Personal Autonomy and Situations of Dependency' which has been used as an example of good practice in relation to Article 31 of the UNCRPD. This large statistical research study was performed with the participation of other official and civil bodies, including organisations of people with

⁵⁵⁶ CRPD/C/AUS/1, 'Report to the Committee on the Rights of Persons with Disabilities: Australia' (3 December 2010), at para 202-205.

⁵⁵⁷ CRPD/C/AUT/1, 'Report to the Committee on the Rights of Persons with Disabilities: Austria' (2 November 2010), at 49.

disabilities and their families. CERMI state that these statistical sources, used and worked well, can serve the purposes of Article 31 perfectly.⁵⁵⁸

5.27.3. Key policies and programmes in Northern Ireland relevant to Article 31

Article 31 of the UNCRPD introduces a new element to human rights treaties. It requires States Parties to specifically collect disability data and statistics to facilitate UNCRPD implementation. This process forms part of the practical steps that are necessary to support reform. These steps, specifically, Articles 31 to 33 UNCRPD, have been termed the 'Dynamic of Reform' by the European Foundation Centre.⁵⁵⁹

Statistics are an invaluable policy tool, and the collection of data and statistics, if robust, can contribute to the design of policies and legislation which promote and protect the rights of persons with disabilities.⁵⁶⁰ As previously reported, Article 31(1) UNCRPD identifies the purpose of data and statistics collection and outlines the standards to be used for the collection, maintenance and use of this information.

More specifically, collection of disability statistics and data should enable States Parties to formulate, implement, monitor and evaluate policies and programmes in order to give effect to the UNCRPD.

In relation to the statistical and data requirements of the UNCRPD it was noted early in the study that statistics on policies and programmes were very rarely disaggregated to give information on persons with disabilities or to type of disability(see for example the comments in Article 9 and Article 10). When this was questioned by the research team, two answers emerged; firstly that it had not been considered (there was a lack of awareness for the need, or no-one had asked for it, it was not in the work plan or there was no funding to facilitate it) or secondly that the number of persons with disabilities collected in a general study was so small that disaggregation would increase the probability of the identification of individuals.

“Statistics not available and unable to gather the information, they (the State) had not thought about statistics for PWDs” (Persons With Disabilities).⁵⁶¹

⁵⁵⁸ CERMI (2009), 'Human Rights and Disability: Spain Report 2009', 27 May 2010, at 43.

⁵⁵⁹ 'The European Foundation Centre (EFC) (2010). Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, 'The European Foundation Centre (EFC), VC/2008/1214

⁵⁶⁰ See inter alia EDF statement during the UN CRPD negotiations in 2003 at the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities

⁵⁶¹ Comment from Scoping Focus Group 15/12/2010

This study is aware that in the autumn of 2010 the ODI had issued a list of measures it intended to use in the State report and requested statistics from Northern Ireland. It is understood that a statistical report highlighting Northern Ireland figures where possible has been sent to ODI for inclusion in the UNCRPD State report.⁵⁶² The OFMdfM has previously commented in relation to a statistical strategy for the UNCRPD that: following the publication of the UK State report that the IMNI (NIHRC and the ECNI) will produce their parallel report bringing to attention any areas of concern they may have; the UN Committee will examine the UK Report and formulate a response; and that the production of representative statistical data on persons with disabilities will be examined throughout this process including any engagement events⁵⁶³. Difficulties will however arise in the state report because of the different service provision used in the constituent parts of the UK.

A participant reported that, **“statistics would not be comparable between GB and NI due to different systems being in operation”**⁵⁶⁴ (education and health)

It is currently extremely difficult to measure the effectiveness of government policies in relation to people with disabilities. This is due to a lack of co-ordinated and effective monitoring to quantify the impact of policy change. For example, there is no current disaggregated data published for the digital inclusion of disabled people in Northern Ireland⁵⁶⁵.

“Need to match statistics to policy areas and awareness of what currently exists”⁵⁶⁶

“Helpful/important to know number of disabled people in employment (feeling statistics are weak or not well known)”⁵⁶⁷

“No disability hate crime statistics on NISRA (January 2011)”⁵⁶⁸ although these were available on the PSNI website.

The DHSSPS Draft Equality Action Plan 2011 summarised the difficulties in relation to data collection very well when it was commented that ‘generally the HSC data systems do not record all the s75 category information and this means that a lot of the findings are anecdotal and some were based

⁵⁶² Information from OFMdfM, February 2011. This report is not publically available at the time of writing.

⁵⁶³ Correspondence from OFMdfM Disability Unit 25/2/11 Correspondence from OFMdfM Disability Unit 25/2/11

⁵⁶⁴ Ibid

⁵⁶⁵ See for example the Office for National Statistics (2011). Internet Access Quarterly update, 18/5/2011. Office for National Statistics:UK

⁵⁶⁶ Comment from a IMNI Conference workshop participant 1/12/11

⁵⁶⁷ Comment from a IMNI Conference workshop participant 1/12/11

⁵⁶⁸ Ibid

on findings from outside Northern Ireland or from reports produced by representative/stakeholder organisations. In addition, in some cases the sources were fairly dated and the material may no longer be valid'.⁵⁶⁹

The disaggregation of data is essential as disabled people are not a homogenous group and policies which have a positive effect on the majority of disabled people may adversely affect another group in their enjoyment of a particular right or service. Information is widely dispersed and is often based on anecdotal information.⁵⁷⁰ Systems are not monitored or policed and where information is available it is not readily accessible or available in formats required by disabled people.

“Statistics need to be accessible (especially websites) in suitable formats and in one place. Like the children section in ARK”.⁵⁷¹

Recent research on services or attitudes which have been carried out remains unexamined in relation to disability (sometimes due to the small number of disabled people responding) or where specifically related to disability, large sections remain unpublished⁵⁷² or remains unexamined (e.g. the adult Northern Ireland Life and Times survey section on disability in the 2009, funded by the ODI).⁵⁷³ This appears to be related to a lack of funding for research in this area or a lack of central direction and coordination.⁵⁷⁴

Evidence from the research suggests that capacity building and awareness is required to enable people with disabilities and their representatives to fulfil the requirement for involvement and participation in the monitoring process under Article 33(3).

“Capacity building is required for disabled people to fully take part in the monitoring process under the UNCRPD”.⁵⁷⁵

It was reported that they (representatives and disabled people) **“did not know where to look for data and statistics and that there was little signposting”**⁵⁷⁶. They reported statistics were **“hard to find”**.⁵⁷⁷

⁵⁶⁹ DHSSPS (2011) Equality Action plan. <http://www.dhsspsni.gov.uk/showconsultations?txtid=46900>.

⁵⁷⁰ Ibid

⁵⁷¹ Ibid

⁵⁷² Northern Ireland Statistics and Research Agency (2007). The Prevalence Of Disability And Activity Limitations Amongst Adults And Children Living In Private Households In Northern Ireland. NISRA: Belfast

⁵⁷³ Northern Ireland Life and Times Survey (Adult) 2009 <http://www.ark.ac.uk/nilt/2009/>

⁵⁷⁴ Meeting with ARC 27th October 2010

⁵⁷⁵ Comment from a participant in the third Thematic Focus Group Workshop on the 18/2/2011, Article 9 and 21 'Access to information' and Article 31 on 'Statistics and Data Collection

⁵⁷⁶ Ibid

⁵⁷⁷ Ibid

There appears to be little statistical capacity amongst the Northern Ireland voluntary sector to fulfil this function (e.g. few voluntary sector organisations have the software or training required to examine raw data if supplied by the State). Change is also required in the interaction between the State and persons with disabilities and their representatives in that 'State Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others. This will mean an examination of how and where statistics are published and a change in the attitude of staff from 'why do you want them' to 'how can we get them to you'.

One participant in one of the thematic focus groups reported that they had tried to find out the number of amputees in Northern Ireland but that figures had not been available. When they made enquires by phone they had been asked by a member of staff, why they wanted to know.⁵⁷⁸

The participants in the thematic focus groups also reported that they were unaware of schemes to have input into data collection. Participants commented that greater government coordination is required and that information directly concerning disabled people should be centralised. Participants recognised that disability is a diverse issue and responsibility crosses departments but commented that coordination is crucial as is consultation with disabled people at an early stage and in drawing up action plans.⁵⁷⁹

Participants commented that many disabled people have no access to academic reports which are on pay to see services and they commented that an abstract reporting service such as that supplied by ARC on children and young person's research would be useful.⁵⁸⁰ It was reported that an **"easy read version of statistics would be useful"**.⁵⁸¹

The lack of sufficient disability-specific statistics and data in Northern Ireland is however not unique. A 2010 European Foundation Centre (EFC) study⁵⁸², found that 'they could not identify adequate information within the Member States of the EU regarding practices related to the collection of statistics and data based on a social model of disability and being disaggregated, as appropriate, to support policy development and the monitoring of policy implementation'. They further commented, 'It logically follows that there is a need for further research in this field. Regarding the EU, instruments

⁵⁷⁸ Ibid

⁵⁷⁹ Ibid

⁵⁸⁰ Ibid

⁵⁸¹ Ibid

⁵⁸² The European Foundation Centre (EFC) (2010). Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, 'The European Foundation Centre (EFC) VC/2008/1214

listed in the Council Decision concerning the conclusion of the UNCRPD have established methodological frameworks and systems for the compilation of reliable and comparable data in the fields of social protection and inclusion. However, it appears that there is a need to review existing instruments and evaluate whether (or not) such instruments are appropriate for the compilation of disaggregated data on disability for matters covered by the Convention'.⁵⁸³

Some studies do exist, for example, the Disabled Women in Northern Ireland, Situation, Experiences and Identity⁵⁸⁴, the report of the Promoting Social Inclusion (PSI) Working Group on Disability⁵⁸⁵, the GB only report on the Experiences and Expectations of Disabled People⁵⁸⁶ and The Prevalence of Disability and Activity Limitations Amongst Adults And Children Living In Private Households In Northern Ireland⁵⁸⁷ and further data continues to be gathered from sources such as the 2011 Census. However while this data clarifies the background in which the UNCRPD will operate, often it does not refer to Northern Ireland or it does not specifically support policy development and monitoring related to the implementation of the UNCRPD.

This research team would add that it is insufficient only to have the data; it must be disseminated in suitable formats to be useable by people with disabilities and interested parties to challenge the State's implementation of the convention under Article 31 (2 and 3) and Article 33(3). The research team, through contact with stakeholders and public bodies, has noted that producers of statistics are citing legislative safeguards to ensure confidentiality and respect for the privacy of persons with disabilities as reasons for not making disaggregated data available for examination. Statistical producers comment that this is due to the small numbers of disabled people involved in surveys⁵⁸⁸ or reporting such matters as hate crime⁵⁸⁹. They argue that these small numbers may allow the identification of these individuals. It is the view of the research team that a result of the aggregation of this data is that issues cannot be identified by campaigners or the relevant public authority. As previously reported under Article 9 and

⁵⁸³ The European Foundation Centre (EFC) (2010) Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, 'The European Foundation Centre (EFC), Page 12, VC/2008/1214.

⁵⁸⁴ ECNI (2003) Disabled Women in Northern Ireland: Situation Experiences and Identity.

⁵⁸⁵ OFMdFM (2009) Report of the Promoting Social Inclusion Working Group on Disability

⁵⁸⁶ Williams B., et al, (2008) Experiences and Expectations of Disabled People, ODI.

⁵⁸⁷ Northern Ireland Statistics and Research Agency (2007). The Prevalence Of Disability And Activity Limitations Amongst Adults And Children Living In Private Households In Northern Ireland: Bulletin 1 July 2007 Northern Ireland Statistics and Research Agency:Belfast.

⁵⁸⁸ For example only 8% of respondents to the Young Life and Times Survey were disabled or had a long term illness) see <http://www.ark.ac.uk/ylt/2010/techinfo.html> and <http://www.ark.ac.uk/ylt/2010/Background/DISAB1.html>

⁵⁸⁹ See section 5.9 on Hate Crime above.

29, many disabled people report that they are excluded from taking part in society by access issues, this includes the opportunity to take part in surveys and have their views considered.

The research team is concerned that the State may rely on Article 31 (1a and 1b) UNCRPD in relation to confidentiality and respect for privacy in order to maintain the current position rather than examine different methods of data collection and processing which while ensuring compliance with these requirements will allow an examination of the requirements of the Convention.

It is recommended that researchers and policy makers take a more open and wider approach to the collection of data on disability and from disabled people by involving disabled people in research design and data collection, and looking at alternative methods of data collection (such as focus groups) in order to drive the response rate from the low figures (8% in the Young Life and Times survey 2010⁵⁹⁰) currently obtained by researchers. Alternatively specific research studies should be targeted at disabled people to gather information as part of wider studies. A study of disability friendly data collection methods and disability targeted studies in other jurisdictions with the involvement of persons with disabilities and other interested parties will assist in this process.

The lack of availability of disaggregated data also has implications for Equality Impact Assessments (EQIA). It has been noted during this study that it appears common that only the screening process under Section 75 is undertaken. A full EQIA, following the Commission's Practical Guidance on Equality Impact Assessment (2005), is often not carried out with respect to persons with disabilities (and some other groups) due to a lack of data. From conversations with stakeholders it appears that the full EQIA is not carried out because there is no evidence of any specific problem. The situation in relation to EQIAs is set out in a number of guidance papers published by the ECNI on their website and are outlined below.

Schedule 9 4 (2) of the Northern Ireland Act 1998 specifies what an equality scheme must include. The list of requirements cited does not include reference to an audit of inequalities or an action plan. However Section 75 of the Northern Ireland Act 1998 – A guide for Public Authorities (ECNI: 2010), states (at page 46) that 'In order to effectively demonstrate that a public authority has paid due regard to the need to promote equality of opportunity and regard to the desirability of good relations through the implementation of its equality scheme, the Commission recommends that a public authority develops action plans/action measures to promote equality of opportunity and good relations'.

⁵⁹⁰ <http://www.ark.ac.uk/ylt/2010/Background/DISAB1.html>

The recommendation was developed from a finding of the Final Report of the Section 75 Effectiveness Review that 'Overall, Section 75 has had a considerable positive impact on how public policy is developed; however, the impact on the lives of individuals in terms of the implementation of these policy outcomes is less certain'. 'The Commission considers that the development of Section 75 action plans by public authorities will enable a greater focus on outcomes for people belonging to the Section 75 categories'.⁵⁹¹

An audit of inequalities is considered as the first stage in the development of a Section 75 Action Plan. An audit of inequalities is a systematic review and analysis of inequalities which exist for service users and those affected by a public authority's policies so as to enable an authority to identify potential functional areas for further or better discharge of the Section 75 statutory duties and therefore inform key strategic actions.

The 2010 guide states (at page 47) that 'the Commission will not consider the content of action plans or action measures as part of the approval process for equality schemes. However the Commission recommends public authorities submit these along with their equality schemes in order to demonstrate their commitment to implementing their equality schemes'.

There is also valuable guidance in relation to how an EQIA should be carried out in Section 2 of the Commission's Practical Guidance on Equality Impact Assessment (2005), which sets out advice with respect to the preparations that a public authority should take with respect to the collection of available data and research for an EQIA:

'Public authorities will need to consider how they will collect the information which will enable them to make a judgment of the extent of impact on the nine equality categories...The following guidance outlines the approach to be adopted at this stage:

- Collect and analyse existing quantitative data by relevant equality category as a minimum base from which to judge outcomes;
- Use qualitative or evaluative research or information gathered by government and bodies such as voluntary, community and trade union organisations;
- Identify gaps in available information for equality categories and where more detailed data are needed, take steps in order to have the optimum information on which to consult and base subsequent decisions;
- If necessary, commission new data (qualitative or quantitative). As outlined above cooperation within and between sectors should be considered; and

⁵⁹¹ Clarification from ECNI July 2010

- Relevant, reliable and up-to-date information is essential. Statistics alone do not provide reasons or explanations for differences. Public authorities must therefore institute a system of information gathering across all nine equality categories to supplement available statistical and qualitative research. While the collection of relevant data is important, public authorities must be aware that particular issues of sensitivity and confidentiality may arise in relation to disability, sexual orientation and political opinion. Public bodies must recognise the particular benefit of discussion and information gathering with groups representing people with disabilities and of different sexual orientations, in the absence of extensive data on these matters, among their employees and recipients of services' (page 11). Unfortunately this recommended systematic approach does not appear to be universally applied (see comments on DHSSPS Draft Equality Action Plan 2011 above). It is strongly advised (in the latest Section 75 Guidance) but not legally required that public bodies need to carry out an audit of inequalities of people using their services.

"To ensure that measures included in an action plan are relevant to the functions of a public authority, the Commission recommends that they are developed on the basis of an analysis of inequalities that exist for the public authority's service users and those affected by its policies. The Commission recommends that public authorities undertake an 'audit of inequalities' to inform the development of their action plans".⁵⁹²

It should also be noted that not all public bodies have moved to the new guidance and that this move and inspection of the new Equality Schemes is an ongoing process by the ECNI⁵⁹³ on a phased basis so as to avoid consultation overload for public authorities' stakeholders. The final tranche of schemes are due to be submitted to the Commission by 1 November 2012. Until a public authority has its revised scheme approved by the Commission, its current Equality Scheme will continue to stand.⁵⁹⁴

The research team would advise that consideration be given to considering a change in the law to make inequality audits and the guidance contained in Section 2 of the Commission's Practical Guidance on Equality Impact Assessment (2005) mandatory (were no data exists) for all policies.

⁵⁹² ECNI (2010). Section 75 of the Northern Ireland Act 1998: A Guide for Public Authorities. ECNI:Belfast. page 48

⁵⁹³ [http://www.equalityni.org/archive/word/MasterOperationalTimetable\(V12\)updatedMay2011.doc](http://www.equalityni.org/archive/word/MasterOperationalTimetable(V12)updatedMay2011.doc)

⁵⁹⁴ Clarification received from the ECNI in July 2011

5.27.4. Results from the questionnaire and the focus groups

The early stage research (literature review and contact with stakeholders) carried out for this study suggested the 'cross cutting' importance of Article 31 in the implementation of the UNCRPD. This resulted in Article 31 being part of the conference questionnaire and workshop material. The workshop revealed that there were some concerns about the availability of disability data and the questionnaire results revealed that Article 31 was rated as the 4th highest priority gap area by disabled people (n=10) and 8th (n=18) by the non disabled group in the quantitative question 12 at 10.3.12. However this was not reflected in the open questions. Clarification was sought from the conference workshop and the scoping focus groups.

The scoping focus groups provided further clarification and it was noted that information and statistics and data collection was considered as a combined area by participants and was consistently rated in the top three policy gap areas by both disabled people and State and voluntary sector representatives. Access to information appeared to be more important than the statistics themselves however they were considered to be effectively one area and therefore this section should therefore be read with the results from Article 9. This relationship was explored further in the thematic focus group in February 2011 and reported in Section 13.

5.27.5. Key area

Article 31 was initially revealed as a crucial area for the implementation of the UNCRPD by a literature review and contact with stakeholders. However combined with the accessibility of the data as required by 31(3) it was confirmed by disabled people and State and voluntary representatives as being a key area. It is considered an important cross cutting measure which has significant impact on the majority of people with a disability in influencing the policies and programmes the State develops and in the monitoring process under Article 33.

6. Key areas where there are substantive shortfalls between public policy and programme delivery in Northern Ireland relative to the requirements of the UNCRPD

6.1. Identification of key areas

The terms of reference (TOR) for this project identified a set of Prioritisation Criteria as examples of the criteria to be considered when assessing any key strategic issues / barriers to the full implementation of the Convention. These were:

- 1 The issue is one of the most intractable or persistent and/or one on which little progress is being made;
- 2 The issue is disproportionately damaging i.e. the group affected may be small but the impact substantial;
- 3 The 'direction of travel' is negative i.e. existing evidence shows a worsening experience for disabled people.

These mirrored the criteria used by the Office for Disability Issues (ODI) and it was useful to retain this framework to ensure fit with the national comments on the implementation of the UNCRPD. That being said, the working definition of a key area has been defined in the project as: An area where a requirement or set of requirements of specific articles of the Convention appear to be inadequately implemented to the extent where they impact on the fundamental compliance of State policy and programmes with the requirements of the UNCRPD and / or where they fulfil one of the Priority Criteria set out in the ECNI's terms of reference for the project (page 6). Implicit in this definition is the central importance of cross cutting articles and themes which impact negatively or positively on other articles in their implementation, monitoring and accessibility to persons with a disability. A key area is thus a product of the complex interaction of the varying impact of the obligations contained in various articles of the CRPD in conjunction with the policy and programmatic situation in Northern Ireland.

As the study progressed it became clear that the selection of key areas would be problematic as there was little evaluation evidence in relation to the outcomes of policies and as reported in Article 31 the absence of disaggregated statistics and patchwork data collection did not allow a comprehensive analysis of policies.

Secondly that there was no one source for an assessment of the current policies either in the local jurisdiction through the OFMdfM or nationally through the State report.

Thirdly the study did not have access to Government planning with respect to the UNCRPD and the wider plan for greater inclusion as the OFMdfM response to the Promoting Social Inclusion (PSI) working group on disability has not yet

been published and neither the OFMdfM nor UK State reports were available at the time of writing.

In the absence of this information the research examined what source material was available from the UN and its committees, general commentary on human rights and specifically on the UNCRPD and any available research or review papers. Enquiries were also undertaken with the front line providers of services, policy makers, and key stakeholders and most importantly with persons with disabilities and their representative groups.

From this research it became clear that there were a number areas of concern which were of vital importance to the research, group or individual highlighting them. In order to choose what was most relative to a successful implementation of the UNCRPD, the research team had to consider which areas will have the most impact on the cultural change required and will develop a firm evidential based foundation on which to build the development of successful policies and the monitoring of these policies, allowing the state to be successfully challenged and the lives and choices of disabled people to be practically improved.

A further factor was the extent to which key areas were cross cutting in their impact. As previously noted, cross cutting articles are those which have a fundamental influence on the delivery of all articles. Good delivery on these articles will have a positive effect on the effectiveness of a wide range of articles, whereas a poor implementation will have a negative influence on articles.

As stated, a major influence of the selection of the key areas was the views of disabled people and their representatives and the front line service providers and policy makers. The research team wish to pay tribute to the efforts of all those who took part in the questionnaire research, focus groups and to those who gave freely of their valuable time.

Following the initial phases of the research, the research team considered all the available evidence from the literature review, the conference questionnaire and workshop, discussions with key stakeholders in Government and the voluntary sector and submissions from the Disability Action membership organisations. This was a difficult process and the three chosen key areas were judged to meet the criteria set out by the TOR and to be cross cutting to the extent that they are critical to the successful implementation of the UNCRPD. These three areas are not exhaustive or exclusive of others which would be of legitimate concern to people with disabilities. It should be clear from the evidence contained in this report that further areas notably independent living, employment and education could have been added to the list.

The three chosen areas were further tested by the scoping focus groups and explored through three thematic focus groups and as a result of this process, the research team, and most importantly the participants in the study are

satisfied that the 3 key areas have been correctly identified.

The three areas identified were:

- 1 awareness raising;
- 2 participation in political and public life;
- 3 statistics and data collection and the availability of accessible information.

6.2. Assessment of the key areas of non-compatibility of public policy and programmes in Northern Ireland with respect to Articles 5-31 of the UNCRPD

A detailed review of the policies and shortcomings in relation to the three key areas are detailed in the section on Articles 8, 9, 21, 29 and 31, although references to these have been made throughout the report.

The key areas are interrelated with effects on each other and on all articles of the Convention. If people live in a culture in which they are not aware of the rights, requirements and the barriers which prevent disabled people from taking part in society, they will view disabled people as people to be protected and cared for and not as full members of society. Society will not ask them for their views, they will not supply the accessible information people with disability require to access services or the information and statistics needed to challenge society. Society will not provide the reasonable adjustments they need to participate. Society may ask them for their views during a consultation but will not ask them what they want or require first. Society will not ask them to participate in the monitoring of policies which affect them. People with disabilities will therefore not have the tools to challenge society and will continue to be outside.

6.2.1. Awareness Raising

Research from the questionnaire and focus groups together with the examination of the requirements of the UNCRPD in stage 1, suggests that awareness raising is central to a number of articles and the implementation of the convention. This view is supported by Don MacKay (the Chair of the United Nations Ad Hoc Committee on Convention on Disabilities) who commented, "Civil society needs to raise awareness both within its constituent groups, and within society as a whole, about the new Convention, the paradigm shift it embraces, and the rights it enshrines"⁵⁹⁵. Lord Ashley of Stoke commented during a House of Lords debate on the UNCRPD that, "We need to tackle the evident lack of knowledge of disabled people's rights and their failure to claim them; a major awareness campaign is a priority"⁵⁹⁶.

⁵⁹⁵ Phillip French, P (2007). Disability Studies and Research Institute, Human Rights Indicators for People with Disability- A resource for disability activists and policy makers incorporating an introduction and commentary to the United Nations Convention on the Rights of Persons with Disabilities, P8

⁵⁹⁶ <http://www.publications.parliament.uk/pa/ld200607/ldhansrd/text/70625-0009.htm>

Bob Collins, (Chief Commissioner of the Equality Commission for Northern Ireland) stated at the IMNI Conference on the UNCRPD that Awareness raising "...is important not only for people with disabilities and representative organisations, it's also important to raise awareness with policy-makers and to ensure that they are conscious of the obligations on the State Party in respect of each Convention article".⁵⁹⁷ The Promoting Social Inclusion (PSI) working group on disability also recognised the central nature of awareness raising in promoting inclusion commented that, "Our goal is to create a culture where positive attitudes are promoted towards disabled people, one in which their needs are mainstreamed into all aspects of life and where all services are delivered on a rights basis and in an appropriate and supportive way".⁵⁹⁸

A participant in the focus group for this research said **"They assume that we can't think or speak for ourselves, work, have children, need contraception, or smear tests ... we can't have a family, we have a disability, I am not a non person, they treat us as non persons."**⁵⁹⁹

Awareness raising permeates into all aspects of the UNCRPD and the real lives of people with disabilities, from the driver on the bus thinking about stopping for a disabled person, to the High Court judge giving someone with a speech impediment more time and the Jury not assuming they are nervous or lying and the policy maker realising that they must speak to a group of disabled people before a policy is mapped out.

Article 8 of the UNCRPD imparts on the State, obligations in relation to the raising of awareness regarding people with disabilities; fostering respect for the rights and dignity of persons with disabilities; combating stereotypes, prejudices and harmful practices in all areas of life, including those based on sex and age. These duties must be effective, immediate, and appropriate.

The Independent Mechanism for Northern Ireland (IMNI) has clearly stated that they should not be considered as an organisation to decide upon legislation and policies, or to engage in other decision-making processes, for the State Party's implementation of the Convention. The IMNI's role is to help facilitate implementation through its assessment of the State Party's actions to encourage full implementation of the Convention's provisions.

The research team agrees with the comments of the IMNI in that the independent body should not perform the function reserved for the State especially such a critical requirement as those under Article 8. Only the OFMdFM has the authority to undertake the awareness raising function which will inevitably be cross departmental requiring considerable authority

⁵⁹⁷ http://www.equalityni.org/sections/default.asp?cms=News_Speeches&cmsid=1_11&id=261&secid=1_1

⁵⁹⁸ OFMdFM (2009). Report of the Promoting Social Inclusion Working Group on Disability, Page 13, OFMdFM: Belfast

⁵⁹⁹ Comment made by a participant with disabilities in the Representative Focus Group on the 14/1/2011 Page 13, OFMdFM: Belfast

and resources and it is suggested that the responsibility in this matter should remain firmly with them. It may be that a secretariat with specialist knowledge of the disability sector is required by the OFMdfM in order to carry out this function and the necessary oversight required and that this group's progress is monitored by the IMNI, however this is a matter for conjecture pending the release of the OFMdfM report.

The scale and scope of action required in raising awareness throughout society and the scope of the article to include awareness at the family level, is beyond that contained in the disability duties, which under the Disability Discrimination Act 1995 (DDA) applies only to public authorities. The UNCRPD duties under Article 8 will require intervention in all functions of the State and will include changing stereotypes, prejudices and harmful practices towards persons with disabilities through the media, education and attitudinal influencers such as the churches and political parties. The researchers found that while the scale of change required is recognised by some key stakeholders, clear central direction and coordination is vital. The challenge to society will be to not just incorporate the necessary changes into the current disability duties but to ensure that areas such as family attitudes and groups, for example, private sector organisations etc, which are not included in these duties, are addressed.

It is essential that not only are the recommendations and guidance of the ECNI in respect of the effectiveness review on monitoring and enforcements of the disability duties made compulsory and fully implemented⁶⁰⁰, but that people with disabilities become fully involved in the process. The requirements of Article 8 must be incorporated into the duties of public bodies, although the current guidance, monitoring and enforcement systems are designed solely to fulfil the disability duties under the DDA and consideration should be given as to whether Article 8 can be incorporated into the current systems. This research has noted that the UNCRPD is considered by many to be aspirational in contrast to the disability duties and a clear direction as to the status and impact of the UNCRPD is required by government to all departments and bodies.

Coordination across Departments and at different levels under Article 33(1) UNCRPD is vital to ensure the implementation of UNCRPD and the positive impact of the Convention on the lives of persons with disabilities. As part of this strategy it is essential that the duties under the DDA are coordinated and cross referenced to ensure that they are not solely departmental or function based and reflect the requirements of UNCRPD.

“Need to think bigger – national campaign – changes in schools and prisons etc – make people think, for example about access.”⁶⁰¹

⁶⁰⁰ ECNI (2009). Effectiveness of the Disability Duties, Review report. ECNI: Belfast

⁶⁰¹ Comment from a participant of the Service User Scoping Focus Group on the 15/12/2010

“Those that have been there need to be behind awareness raising.”⁶⁰²

The research findings from the focus groups have suggested that education is the key to the required change in attitudes, for example:

“School children need to be taught about disability in the curriculum”⁶⁰³.

There have been relatively successful campaigns to address sectarianism, homophobia and racism in schools, however, the evidence from the focus groups and detailed in section 5.4, suggests that disability remains a lower priority. However, a thematic study has not been carried out and the UNCRPD remains relatively unaddressed. It is suggested that an early clear directive from the State, to address the issue, supported by information and monitored by an inspection regime, would give benefits far beyond the school gates and will influence family behaviour and attitudes.

6.2.2. Participation in political and public life

“Inclusion means include me”⁶⁰⁴

Participation The identification of this key area reflected the evidence from the majority of participants in this study and the available literature that disabled people were not being asked in a coherent and universal way, their views on policies and programmes that affect them as citizens in Northern Ireland. Article 29 is reinforced by the fundamental principle of “full and effective participation and inclusion in society”, provided for in Article 3(c) UNCRPD, and by the general obligation “to closely consult with and actively involve persons with disabilities” in all aspects of decision-making, provided for in Article 4(3) UNCRPD. “Read in conjunction with Articles 3 and 4, Article 29 provides one of the clearest expressions in international human rights law of the right to participate in decision-making”.⁶⁰⁵

As previously detailed, the research suggests that the establishment of a Participation Network, similar to that funded by the OFMdfM for Children and Young Persons, to act as an expert interface between government and disabled people may be effective in reducing the lack of effective participation of and consultation with disabled people and aid State compliance with Article 29.

⁶⁰² Comment from a participant of the Representative Scoping Focus Group on the 14/1/2011

⁶⁰³ Comment made by a participant in the Service User Focus Group on the 15/12/10

⁶⁰⁴ Comment made by a participant in the Service User Focus Group on the 15/12/10

⁶⁰⁵ The European Foundation Centre (EFC) (2010). Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, ‘The European Foundation Centre (EFC), 2010, VC/2008/1214

Throughout Article 29 there is an emphasis not only on 'full' participation, but on 'effective' participation. The obligation to ensure the latter is clearly significant in assessing the adequacy of the range of policies and programmes which aim at delivering on its obligations.

Participants in the focus groups stressed the requirements for meaningful participation and not merely token consultation and the Ask First campaign⁶⁰⁶ by the Children's Participation network was seen as good practice.

Participants in the focus group on participation commented that they strongly believed that they were consulted at the end of processes, not at the beginning of the formulation of policy and that any consultation was only in relation to disability issues and not on other issues for example the environment. They believed that this was consultation rather than participation in the process as required by the UNCRPD. The group also commented that there appeared to be a lack of action coming from consultations. This form of consultation rather than true participation is also contrary to the guidance issued by the various organs of the State. An example of these is the excellent practical guide to policy making issued by the OFMdFM⁶⁰⁷, which encourages policy makers to actively involve front line staff and service users early in the policy making process. Traditional models of engagement which place people at the receiving end of the decision making processes are still in use by Government. This is not confined to disabled people but was also expressed by the Seven Towers residents during discussions on improvements to their living conditions.⁶⁰⁸

As reported in Article 29, a lack of meaningful consultation was also noted in the 2009 study for the ECNI⁶⁰⁹ which noted that out of the 21 public authorities assessed in relation to their Disability Action plans, eight provided evidence they had consulted or involved disabled people in the production of their plans. However, 13 public authorities provided little evidence of meaningful consultation in terms of the activities undertaken, by reporting in detail on these activities and the outcomes of these activities. None of the 21 public authorities assessed in the research reported having systems in place to monitor and evaluate their Disability Action Plan as a whole. The report noted a lack of accessible formats for the plans which it suggested creates barriers to participation.

⁶⁰⁶ Participation Network (2010). Ask First - Northern Ireland Standards for Children and Young People's Participation in Public Decision Making, Participation Network.

⁶⁰⁷ OFMdFM, A Practical Guide to Policy Making, <http://www.ofmdfmi.gov.uk/policylink>

⁶⁰⁸ Seven Towers Monitoring Group (2009), Further Report on Progress of Human Rights Indicators January 2009

⁶⁰⁹ ECNI (2009). Effectiveness of the Disability Duties, Review Report, ECNI: Belfast

In relation to capacity building the participants in the focus group on participation⁶¹⁰ commented that capacity building of disabled people was required in order to equip them with the skills required to participate. These included lobbying skills, information about government systems and how to access information. They suggested the increased use of user groups and discussions, but commented that people would only join these if they knew action was coming from them. They did however believe that consultation with disabled people would increase once the State become more aware of the UNCRPD and the requirements of disabled people. The group reported that there should be one contact point within each department for participation however that the process should be overseen centrally perhaps by a Participation Network.

The group reported that people wishing to consult with persons with disabilities should consult with them at an early stage in policy formulation. They should also consider the additional expenses including transport and communication support and time required by some disabled people to participate. The group suggested a standardisation of practice and that action should be taken to resolve any identified problems.

Whilst the situation in relation to the consultation of disabled people and access to information is concerning, it is telling that the focus groups believed that the situation would improve when the UNCRPD began to be implemented. Significant change is required in Government practices on engagement and the provision of information if the current situation is to be improved.

6.2.3. Statistics, data collection and access to information

“Knowledge is power!”⁶¹¹

As previously reported, Article 31 of the UNCRPD introduces a new element to human rights treaties in that it requires States Parties to specifically collect “appropriate information, including statistical and research data” to facilitate UNCRPD implementation. This process forms part of the practical steps that are necessary to support reform. These steps, specifically Articles 31 to 33 UNCRPD, the European Foundation Centre calls the ‘Dynamic of Reform’.⁶¹² Crucial to Article 31, 9, 21 and 33 is the accessibility of data, information and statistics to disabled people, their representatives, the State and the independent monitoring body.

⁶¹⁰ Focus group on Participation in Political and Public life 26/1/2011.

⁶¹¹ Comment from a participant on the Thematic Focus Group on the 19/1/11.

⁶¹² The European Foundation Centre (EFC) (2010). Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, ‘The European Foundation Centre (EFC), VC/2008/1214

In order to effectively monitor and measure the implementation of Convention rights, the Government, the IMNI and civil society require robust data and statistics. However as reported in Article 31, the data on disability and the barriers faced by people with disabilities is limited, may not be accessible and/or does not meet many of the requirements of the UNCRPD. Article 31 is clear in that it is the responsibility of the State to undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.

Some studies do exist for example, the “Disabled Women in Northern Ireland, Situation, Experiences and Identity” study⁶¹³, and further data continues to be gathered from sources such as the 2011 Census. However some data related to disability remains unpublished⁶¹⁴ or unexamined (e.g. the adult Northern Ireland Life and Times survey section on disability in the 2009 funded by the ODI)⁶¹⁵ and this appears to be related to a lack of funding for research in this area or a lack of central direction and coordination.⁶¹⁶

However while this data clarifies the background in which the UNCRPD will operate, it does not specifically support policy development and monitoring related to the implementation of the UNCRPD. In this respect, existing methodological tools should be tested, and if necessary should be modified, with the aim to ensure their suitability for matters covered by the Convention.⁶¹⁷ However as previously reported this research is not aware of any new funding for primary data collection or changes in processes which will be required to fulfil Article 31 of the UNCRPD.

It is expected that the local strategy for the UNCRPD will include an examination of local representative data on disability as currently few of the existing Office of Disability Issues United Nation Convention progress indicators will allow UK wide comparisons. Neither are they directly useful in indicating progress, for example measures of the number of teachers who are qualified in sign language and / or Braille (Article 24-4). Further, data is not currently disaggregated to allow comparison by disability or factors such as gender of the effects of multiple identity on the effectiveness of

⁶¹³ ECNI (2003). Disabled Women in Northern Ireland: Situation Experiences and Identity. ECNI: Belfast.

⁶¹⁴ Northern Ireland Statistics and Research Agency (2007). The Prevalence Of Disability And Activity Limitations Amongst Adults And Children Living In Private Households In Northern Ireland: Northern Ireland Statistics and Research Agency: Belfast.

⁶¹⁵ Northern Ireland Life and Times Survey (Adult) 2009 <http://www.ark.ac.uk/nilt/2009/>

⁶¹⁶ Meeting with ARC 27th October 2010

⁶¹⁷ The European Foundation Centre (EFC) (2010). Study on challenges and good practices in the implementation of the UN Convention on the Rights of Persons with Disabilities, ‘The European Foundation Centre (EFC) VC/2008/1214

health services.⁶¹⁸ It is also of concern that many of these indicators are not currently available in accessible formats or in a centralised location to enable disabled people and their representatives to undertake their monitoring functions under Article 33(3) UNCRPD.

It is important that these sections of the monitoring framework are capable of fulfilling this role, whether that is through adequate resourcing or capacity building or ensuring the availability of information in accessible formats in order to hold the State to account.

As the study progressed it became clear that the availability of the information from the State was as important as the collection of the data and this relates to accessibility requirements in relation to information from Article 9, 21 and 31. Availability of information is necessary for a disabled person to challenge the State, identify problem areas or suggest new solutions. If a disabled person cannot access the website and find the data and then study it in an accessible format, why collect it? Concerted co-ordinated action is required by the State in order to resolve the current situation in relation to inaccessible information but good examples exist such as the Scottish accessible information policy.

6.3. Conclusions

The UN Convention on the Rights of Persons with Disabilities is at an early stage in its global implementation. The significance of many of its articles remains in some instances unclear. The UN Committee on the Rights of Persons with Disabilities is only beginning the process of definitively clarifying the obligations that the Convention contains.

It became clear during the research that obligations with respect to policies and programmes are not 'detachable' from legal obligations. It is vital that the CRPD be interpreted, implemented and monitored as a whole, in the light of the connections and relations between the overlapping obligations of its different articles and underpinning principles.

In conducting this research into disability and the UNCRPD in Northern Ireland, it became abundantly clear just how limited the research base actually is. There is a need for much more research in this area to ensure the full implementation of the Convention. If the situation of disabled people is not known with relative certainty, with respect to the areas of their life covered by the Convention, then it is impossible for the UK and Northern Ireland governments to claim that their human rights are being respected and protected. Effective monitoring of the Convention at national or international level cannot take place without quality research being conducted into the life situations of disabled people in Northern Ireland.

⁶¹⁸ <http://www.dhsspsni.gov.uk/sexualhealthstrat.pdf>

Three priority areas were identified by the literature review and by disabled people and their representatives as key areas where the UNCRPD is not being fully implemented in Northern Ireland with respect to policies and programmes. These were:

- Awareness-raising;
- Participation in Political and Public Life;
- Statistics, Data Collection and Access to Information.

Urgent work by the State, in partnership with disabled people and their representatives, is required to address the identified gaps in policies and programmes, not least in these three priority areas.

It therefore appears that the monitoring function of the Independent Mechanism for Northern Ireland (IMNI), the full participation of civil society and in particular persons with disabilities and their representatives in the monitoring process under Article 33 (3), and the full participation of disabled people in policy formulation will be of vital importance in shaping the OFMdFM response to the UNCRPD in Northern Ireland in the 'living' format as proposed by the OFMdFM.

7. Bibliography: Including academic literature in English on the UNCRPD

Jean Allain, (2008) **Legal Position of Reservations to the UN Convention on the Rights of Persons with Disabilities**, Legal Report 1, (Centre on Human Rights, Disability Action).

Jean Allain, (2009) **Treaty Interpretation and the UN Convention on the Rights of Persons with Disabilities**, Legal Report 2, (Centre on Human Rights, Disability Action).

Pentti Arajärvi, "UNCRPD and the Human Rights of Persons with Disabilities", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009) **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 34-53.

Oddný Mjöll Arnardóttir, "A Future of Multidimensional Disadvantage Equality?" in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 41-66.

Gauthier De Beco, (2011) "Article 33(2) of the UN Convention on the Rights of Persons with Disabilities: Another Role for National Human Rights Institutions?", **Netherlands Quarterly of Human Rights**, Volume 29(1), pp. 84-106.

Dauid Por Björgvinsson, "The Protection of the Rights of Persons with Disabilities in the Case Law of the European Court of Human Rights", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009) **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff, 2009), pp. 141-61.

Rodolfo Cattani, (2010) "Removing Accessibility Barriers to Telecommunications: A Pre-Requisite for Social Inclusion of Persons with Disabilities Contribution from the European Disability Forum", **European Yearbook of Disability Law**, Volume 2, pp. 149-152.

Department of Economic and Social Affairs & United Nations High Commissioner for Human Rights, (2007). **From Exclusion to Equality: Realising the Rights of Persons with Disabilities**, (United Nations, 2007).

Delia Ferri, (2010) "The Conclusion of the UN Convention on the Rights of Persons with Disabilities by the EC/EU: A Constitutional Perspective", **European Yearbook of Disability Law**, Volume 2, pp. 47-72.

Brynhildur G. Flóvenz, "The Implementation of the UN Convention and the Development of Economical and Social Rights as Human Rights", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 257-77.

Caroline Gooding, (2009) "'Promoting Equality?' Early Lessons from the Statutory Disability Duty in Great Britain", **European Yearbook of Disability Law**, Volume 1, pp. 29-58.

Rune Halvorsen, (2010) "Introduction to the Symposium: Digital Freedom and Disability – Lessons from Europe and the United States", **European Yearbook of Disability Law**, Volume 2, pp. 73-76.

Rune Halvorsen, (2010) "Digital Freedom for Persons with Disabilities: Are Policies to Enhance E-Accessibility and E-Inclusion Becoming More Similar in the Nordic Countries and the US?", **European Yearbook of Disability Law**, Volume 2, pp. 77-102.

Thomas Hammarberg, (2010) "Contribution from the Commissioner for Human Rights of the Council of Europe", **European Yearbook of Disability Law**, Volume 2, pp. 153-160.

Ragnhildur Helgadóttir, "The UN Convention in Nordic Domestic Law—Lessons Learned from Other Treaties", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 279-301.

Aart Hendriks, (2010) "The UN Disability Convention and (Multiple) Discrimination: Should EU Non-Discrimination Law Be Modelled Accordingly?", **European Yearbook of Disability Law**, Volume 2, 2010, pp. 7-28.

Bjørn Hvinden, (2009) "Redistributive and Regulatory Disability Provisions: Incompatibility or Synergy?", **European Yearbook of Disability Law**, Volume 1, pp. 5-28.

Holger Kallenhauge, "General Themes Relevant to the Implementation of the UN Disability Convention into Domestic Law: Who is Responsible for the Implementation and how should it be Performed?", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 201-14.

Arlene S. Kanter, (2006-2007) "The Promise and Challenge of the United Nations Convention on the Rights of Persons with Disabilities", **Syracuse Journal of International Law & Commerce**, Volume 34, , p. 287.

Arlene S. Kanter, (2009) "The United Nations Convention on the Rights of Persons with Disabilities and Its Implications for the Rights of Elderly People Under International Law", **Georgia State University Law Review**, Volume 25, p. 527.

Emmanuel K. Kanyemibwa, "Realising the Right to Adequate Food for People with Disabilities in Uganda", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009) **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 186-207.

Hisayo Katsui, "Towards Participation of Persons with Disabilities from the South: Implications of Article 32 of the Convention", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 138-158.

Rosemary Kayess and Phillip French, (2008) "Out of the Darkness into Light?: Introducing the Convention on the Rights of Persons with Disabilities", **Human Rights Law Review**, Volume 8(1), pp. 1-34.

Mary Keys, (2009) "Legal Capacity Law Reform in Europe: An Urgent Challenge", **European Yearbook of Disability Law**, Volume 1, pp. 59-88.

Joel Kivirauma and Matti Laitinen, "The Changing Relationship Between Disability and Education", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 67-98.

Ida Elizabeth Koch, "From Invisibility to Indivisibility: The International Convention on the Rights of Persons with Disabilities", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 67-77.

Jukka Kumpuvuori and Hisayo Katsui, "Achieving Human Security Through Political Advocacy: Linking Ugandan and Finnish DPO Advocacy Work to Article 14 of the UNCRPD", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009) **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 208-225.

Jukka Kumpuvuori and Martin Scheinin, "Treating the Different Ones Differently – a Vehicle for Equality for Persons with Disabilities? Implications of Article 5 of the Convention on the Rights of Persons with Disabilities", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009) **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 54- 66.

Raymond Lang and Ambrose Murangira, "Barriers to the Inclusion of Disabled People in Disability Policy-Making in Seven African Countries", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009) **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 159-185.

Anna Lawson,(2008). **Disability and Equality Law in Britain: The Role of Reasonable Adjustment**, (Hart Publishing,).

Anna Lawson, (2006-2007) "The United Nations Convention on the Rights of Persons with Disabilities: New Era Or False Dawn?", Volume 34, **Syracuse Journal of International Law and Commerce**, p. 563.

Anna Lawson, "The UN Convention on the Rights of Persons with Disabilities and European Disability Law: A Catalyst for Cohesion?", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009) **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 81-109.

Anna Lawson, (2010) "Challenging Disabling Barriers to Information and Communication Technology in the Information Society: A United Kingdom Perspective", **European Yearbook of Disability Law**, Volume 2, pp. 131-148.

Alex Leblois, (2009) "Implementing the Digital Accessibility Agenda of the UN Convention on the Rights of Persons with Disabilities: Challenges and Opportunities", **European Yearbook of Disability Law**, Volume 1, pp. 139-146.

Yanghee Lee, (2009) "Expanding Human Rights to Persons with Disabilities: Laying the Groundwork for a Twenty-first Century Movement", **Pacific Rim Law & Policy Journal**, Volume 18(1), pp. 283-292.

Janet E. Lord and Michael Ashley Stein, "Participatory Justice, the UN Disability Human Rights Convention, and the Right to Participate in Sport, Recreation and Play, in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009) **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 226-240.

Laura Lundy, (2007) "'Voice' Is Not Enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child", **British Educational Research Journal**, Volume 33(6), pp. 927-942.

Don MacKay, (2006-2007) "The United Nations Convention on the Rights of Persons with Disabilities", **Syracuse Journal of International Law & Commerce**, Volume 34, p. 323.

Ron McCallum, (2010) "The United Nations Convention on the Rights of Persons with Disabilities: Some Reflections", **University of Sydney Legal Studies Research Paper**,

Frédéric Mégret, (2008) "The Disabilities Convention: Human Rights of Persons with Disabilities or Disability Rights?", **Human Rights Quarterly**, Volume 30, p. 508.

T.J. Melish, (2007) "The UN Disability Convention: Historic Process, Strong Prospects, and Why the U.S. Should Ratify", **Human Rights Brief**, Volume 14(2), pp. 37-47.

Tina Minkowitz, (2007) "The United Nations Convention of the Rights of Persons with Disabilities and the Right to Be Free from Nonconsensual Psychiatric Interventions", **Syracuse Journal of International Law and Commerce**, Volume 34, pp 405-428.

William N Myhill, (2010) "Law and Policy Challenges for Achieving an Accessible eSociety: Lessons from the United States", **European Yearbook of Disability Law**, Volume 2, 2010, pp. 103-130.

Edson Ngirabakunzi and Hisayo Katsui, "The Right to 'Decent Work' of Persons with Disabilities: Article 27 of the Convention and the Case of Uganda", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009) **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 115-137.

Colm O'Conneide, "Extracting Protection for the Rights of Persons with Disabilities from Human Rights Frameworks: Established Limits and New Possibilities", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009) **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 163-200.

Agustina Palacios and Maria Walls, (2006) "Changing the Paradigm – the Potential Impact of the United Nations Convention on the Rights of Persons with Disabilities", **Irish Yearbook of International Law**, Volume 1 pp. 121-166.

Camilla Parker and Luke Clements, (2008) "The UN Convention on the Rights of Persons with Disabilities: a New Right to Independent Living?", **European Human Rights Law Review**, Volume 4, pp. 508-523.

Michael L. Perlin, "Through the Wild Cathedral Evening': Barriers, Attitudes, Participatory Democracy, Professor Tenbroek, and the Rights of Persons with Mental Disabilities", **Texas Journal on Civil Liberties and Civil Rights**, Volume 13, 2007, p. 413.

Michael L. Perlin, (2009) "'A Change is Gonna Come': The Implications of the United Nations Convention on the Rights of Persons with Disabilities for the Domestic Practice of Constitutional Mental Disability Law", **Northern Illinois University Law Review**, Volume 29, pp. 483-498.

Michael L. Perlin and Éva Szeli, "Mental Health Law and Human Rights: Evolution, Challenges and the Promise of the New Convention", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 241-255.

Jarna Petman, "The Special Reaching for the Universal: Why a Special Convention for Persons with Disabilities?", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 20-33.

Gerard Quinn, "Resisting the Temptation of Elegance: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 215-56.

Gerard Quinn, (2009) "A Short Guide to the United Nations Convention on the Rights of Persons with Disabilities", **European Yearbook of Disability Law**, Volume 1, pp. 89-114.

Richard Rieser, (2008) **Implementing Inclusive Education: A Commonwealth Guide to Implementing Article 24 of the UN Convention on the Rights of People with Disabilities**, (Commonwealth Secretariat).

Michael Ashley Stein & Janet E. Lord, (2008). "The United Nations Convention on the Rights of Persons with Disabilities as a Vehicle for Social Transformation", in **National Monitoring Mechanisms of the Convention on the Rights of Persons with Disabilities**, (Comisión Nacional de los Derechos Humanos de México, Network of the Americas & Office of the United Nations High Commissioner for Human Rights), pp. 1-16.

Michael Ashley Stein & Janet E. Lord, "Future Prospects for the United Nations Convention on the Rights of Persons with Disabilities", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 17-40.

Michael Ashley Stein, Janet E. Lord and Penelope J.S. Stein, (2010). "The Law and Politics of US Participation in the UN Convention on the Rights of Persons with Disabilities", **European Yearbook of Disability Law**, Volume 2, pp. 29-46.

Jeyaprathaban Sujathamalini, "Teachers' and Students' Awareness of and Attitudes Towards the Concept of Inclusion Exemplified in Article 24 of the UNCRPD", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 99-114.

Rannveig Traustadóttir, "Disability Studies, the Social Model and Legal Developments", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 3-16.

Stefan Trömel, (2009). "A Personal Perspective on the Drafting History of the United Nations Convention on the Rights of Persons with Disabilities", **European Yearbook of Disability Law**, Volume 1, pp. 115-138.

Amu Urhonen, "From Devil's Seed to Disabled God – Disability and the Human Rights Approach on the Bible Studies and Practices of Christian Communities", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 267-276.

Riku Virtanen, "Persons with Deafblindness in Light of International Agreements", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 256-266.

Lisa Waddington, "Breaking New Ground: The Implications of Ratification of the UN Convention on the Rights of Persons with Disabilities for the European Community", in Oddný Mjöll Arnardóttir & Gerard Quinn (eds), (2009). **The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives**, (Leiden/Boston: Martinus Nijhoff), pp. 111-40.

Feruza Zagirdinova, "Restrictions of Sexual and Reproductive Rights – The Case of Uzbeki Women with Disabilities", in Jukka Kumpuvuori & Martin Scheinin (eds.), (2009). **United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives**, (The Centre for Human Rights of Persons with Disabilities in Finland), pp. 277-288.

Deborah A. Ziegler, (2010). Inclusion for All: **The UN Convention on the Rights of Persons with Disabilities**, (IDEbate Press, 2010).

8. Appendix 1: IMNI conference questionnaire results

8.1 Introduction

This questionnaire was designed as a scoping exercise to measure and record the attitudes of persons registering for the IMNI conference on the UNCRPD conference on the 1st December 2010 and persons browsing the Equality Commission for Northern Ireland (ECNI) and Disability Action websites in relation to the conference.

8.2 Methodology

A questionnaire containing quantitative and qualitative questions was designed by Disability Action staff and tested by persons with disabilities to ensure robustness. The questionnaire was sent via web-link to the 156 people registered for the conference.

On the day of the conference, additional hard copies were made available for distribution at registration and a verbal reminder was issued during the Disability Action focus group session. Following the conference, a reminder e-mail was sent by ECNI to people who had been registered for the conference, with an extended closure date (10 December 2010) for questionnaire submission. In total the questionnaire was available for 20 days. Alternative formats of the questionnaire were available on request however no requests for these were received by Disability Action staff.

A total of 44 questionnaires were returned (including 24 from the 157 registered conference attendees and 20 from website sources), representing an overall response rate of 28%. The average rate of response for questionnaires is approximately 20% although this varies with the target audience, for example the Disability Rights Commission Hate Crime survey⁶¹⁹ reported response rates from 56% to 9% dependent on the component part of the target population. Response rates also vary dependent on such factors as the length of questionnaire and whether incentives are offered. No incentives were offered in this survey.

The target population for this survey was not homogenous and included elected representatives, persons with a range of disabilities, academics, voluntary sector representatives, carers, public sector representatives and people browsing the ECNI and Disability Action website sections on the conference.

⁶¹⁹ Disability Rights Commission (2004) 'Hate Crime against disabled people in Scotland' March 2004

The sample was self selective in that they had chosen to attend a disability conference, or to respond to a request to complete a questionnaire on the conference website. They were therefore more likely to be interested in disability issues, have access to a computer and the ability to use it. It was also noted that no requests were received to supply questionnaires in alternative formats such as Easy Read or Braille. Taking these matters under consideration it is suggested that while the sample was not representative of the wider community, it served as a scoping group to examine the issues involved and provide suggested areas for further exploration in the more targeted focus groups.

Significance testing was not carried out on the results due to the small sample sizes involved and that the questionnaire was primarily qualitative. Any relevant themes and suggested conclusions were explored further in the planned focus groups.

8.3 Results

Question 1

Table 1: Have you registered for the IMNI Conference?

Response	Count	Percentage
Yes	24	60%
No	16	40%
Skipped	4	

An analysis of the demographic questions 2-5 cross referenced with Question 1 (Registration for the conference) below suggests that the profile of the registered and unregistered (including skipped) respondents was not significantly different and it was decided to use both sets of data for analysis.

Question 2

Table 2: Why are you interested in disability issues? Please tick all boxes which apply to you

Response	All Respondents		Registered for Conference	
	Count	%	Count	%
I am a representative of a public / government body	12	29.3%	7	30.4%
I am a representative of a voluntary / charitable group	26	63.4%	15	65.2%
I am an elected representative	1	2.4%	0	0%
I am a carer	10	24.4%	6	26.1%
I am a person with a disability	12	29.3%	7	30.4%
Other (please specify)	0	0%	0	0%
Answered question	41		23	
Skipped question	3		1	

Question 3

Table 3: What is your gender?

Response	All Respondents		Registered for Conference	
	Count	%	Count	%
Male	12	34.1%	8	34.8%
Female	27	65.9%	15	65.2%
Answered Question	41		23	
Skipped Question	3		1	

The gender makeup of the respondents is reflective of other questionnaire studies at similar events. For example a questionnaire survey at the Lisburn Disability Exhibition and UNCRPD seminar on the 4th and 5th June 2010, found a gender breakdown of 35.4% (n=28) male and 64.6% (n=51) female⁶²⁰

⁶²⁰ McClenahan, S. (2010) Internal Disability Action report on the Disability Exhibition and UNCRPD seminar 4th and 5th June 2010

Question 4

Table 4: What is your age?

Response	All Respondents		Registered for Conference	
	Count	%	Count	%
18-24	1	2.4%	0	30.0%
25-44	11	26.8%	4	17.4%
45-59	25	61.0%	17	73.9%
60-74	3	7.3%	2	8.7%
75+	1	2.4%	0	0%
Answered question	41		23	
Skipped question	3		1	

Question 5

Table 5: Are you a person with a disability?

Response	All Respondents		Registered for Conference	
	Count	%	Count	%
Yes	15	36.6%	8	34.8%
No	26	63.4%	15	65.2%
Answered question	41		23	
Skipped question	3		1	

Question 6

Table 6: Are you able to take part in society on an equal basis with others?

Response	All Respondents		Registered for Conference	
	Count	%	Count	%
Yes	38	92.7%	20	87%
No	3	7.3%	3	13%
Answered question	41		23	
Skipped question	3		1	

The vast majority of respondents to this question commented that they were able to take part in society. When the figure was broken down by the question on disability (Question 5), all respondents (26) who reported that they did not have a disability were able to take part in society whereas in the disabled sample, 80% (12) stated that they were able to take part in society on an equal basis and 20% (3) stated that they were not.

Comments: (Note all comments were from people registered for the conference)

1. **Yes:** " I take part but I don't get it all"
2. **No:** "I live in supported housing and I am caught in the benefits trap as it is not financially viable for me to work unless I was earning a big salary"
3. **Yes:** "This question is subjective, I would say yes in most cases, but it is sometimes difficult, to forge that path, as it takes energy and confidence to try. However, I would say no if this question was solely in relation to employment. Nevertheless, the crux of the matter, in terms of employment is perhaps that when people with a disability go for job interviews, how do they know for sure, that they are not being discriminated against, there is potentially a financial and emotional cost in attempting to challenge issues such as this, especially in such a small community such as Northern Ireland.

I also suggest that whilst direct discrimination is perhaps becoming less common than it was, due to stronger legislation, covert discrimination, such as negative body language and other behavioural attitudes will become more prominent. The difficulty here is that covert discrimination can be subjectively interpreted both by the individual/organisation carrying out the discrimination and by persons with a disability receiving the behaviour, again, it is difficult to prove”.

4. **No:** “I had a stroke. Apart from physical difficulties associated with the stroke I developed epilepsy from my stroke, and I have a communication disorder”.
5. **No:** “These are many and varied and I will be discussing them at the IMNI conference”.
6. **Yes:** “My disability does not exclude me, however, I have a severe dietary requirement which formally people will ask on a form then forget to do anything about. Equally I am told ingredients are checked when they are not, the result for myself is very disabling and has long-term organ damage”.

Question 7

Table 7: How much do you know about the UN Convention on the Rights of Persons with Disabilities?

Response	All Respondents		Registered for Conference	
	Count	%	Count	%
A lot	5	16.7%	2	11.8%
A fair amount	13	43.3%	8	47.1%
A little	10	33.3%	5	29.4%
Nothing	2	6.7%	2	11.8%
Answered question	30		17	
Skipped Question	14		7	

Table 8: Number of people who say they have /have not a disability (Question 5) who know about the UNCRPD (Question 7)?

Response	All Respondents		Registered for Conference	
	Count	%	Count	%
A lot	2	10%	3	30%
A fair amount	7	35%	6	60%
A little	9	45%	1	10%
Nothing	2	10%	1	0%
Answered question	20		11	
Skipped Question	6		5	

The data indicates that the sample of disabled people reported knowing more about the UNCRPD than the sample of non disabled people. This is perhaps not surprising with the efforts of the voluntary sector in informing disabled people although the levels of knowledge amongst voluntary group and government representatives who make up the majority of the non disabled group is disappointing especially as they have reported an interest in disability issues (see Question 2 at paragraph 9.3.2 above).

Question 8

Table 9: What do you think are the three key barriers to disabled people fully participating in society in Northern Ireland?

Response	Count
Answered Question	27
Skipped	17

Whilst the questionnaire revealed a wide range of concerns and attitudes amongst disabled people and representatives some key themes did emerge, these are listed below.⁶²¹

1. Attitudes (23 comments)
2. Access (19 comments)
3. Participation (11 comments)

Other main areas of concern

4. Employment (9 comments)
5. Policy vs. practice (8 comments)
6. Lack of awareness (8 comments)

A full list of comments is attached below at 9.5.

⁶²¹ Doherty G (2011). Analysis supplied to research team by Dr Glenda Doherty, ECNI January 2011.

Question 9

Table 10: What are the three key areas of public policy and programmes in Northern Ireland which best enable disabled people to fully participate in society?

Response	Count
Answered Question	21
Skipped	23

Responses

- i. Legislation and Policy (13 comments)
- ii. Employment programmes (9 comments)
- iii. Effective participation (6 comments)

Other main areas identified

- iv. Accessibility (5 comments).⁶²²

A full list of comments is attached below at 9.5. A full list of comments is attached below at 9.5.

⁶²² Doherty G. (2011) Analysis supplied to research team by Dr Glenda Doherty, ECNI January 2011.

Question 10

Table 11: What are the three main gaps between public policy and programmes in Northern Ireland and the requirements of people with disabilities in Northern Ireland?

Response	Count
Answered Question	22
Skipped	22

Responses

- i. Policy vs. practice (19 comments)
- ii. Lack of awareness (11 comments)
- iii. Employment (8 comments)

Other main gaps identified

- iv. Participation (6 comments)
- v. Access (6 comments)
- vi. Education (5 comments)⁶²³

A full list of comments is attached below at 9.5.

⁶²³ Ibid.

Question 11

Table 12: What are the most important changes to public policy and programmes you would like to see happen to reduce or remove these gaps?

Response	Count
Answered Question	23
Skipped	21

Responses

- i. Policy and legislation (making policy work) (11 comments)
- ii. Participation (10)
- iii. Changing attitudes / Raising awareness (10 comments)

Other changes identified

- iv. Access (4 comments)
- v. Education (4 comments)⁶²⁴

A full list of comments is attached below at 9.5.

⁶²⁴ Ibid.

Table 13: These are some of the areas suggested as having a gap between policy and programmes and the requirements of the UNCRPD. Do you agree? Please rate your agreement with each of these areas below from 5 to 1, with (5) being areas with which you would very much agree and (1) being areas with which you very much disagree.

Answer Options	Very strongly agree 5	4	3	2	Very much disagree 1	Rating Average	Response Count
Health	13	8	6	1	0	4.18	28
Education	14	9	3	0	0	4.33	27
Independent living	17	7	4	0	0	4.46	28
Access to justice (Civil law)	9	9	10	0	0	3.96	28
Accessibility	18	6	4	0	0	4.50	28
Awareness raising	22	3	2	0	1	4.61	28
Personal mobility	12	11	3	1	0	4.26	27
Access to justice (Criminal Law)	9	8	10	1	0	3.89	28
Statistics and data collection ensuring access to these by disabled people	16	4	5	1	1	4.22	27
Equality in the work place	19	7	2	0	0	4.61	28
Mental health and capacity	12	11	4	0	0	4.30	27
Participation in political and public life	17	9	1	0	1	4.46	28
Additional key area and rating							6
Answered Question							28
Skipped Question							16

Question 12

The respondents were asked to rate a number of areas of the UNCRPD using a rating scale. There was a data box for respondents to add any additional areas not listed. This included some areas which it was anticipated would not be been rated as important areas by the previous open questions. The results for the full sample are shown below in Table 13 and Chart 1 on previous page.

Table 13: Additional key area responses

Education (3), Housing (3), Independent living (3)

Transportation (4) Access to sporting and cultural life (3)

“Homeless people and others outside of the system. The system relies heavily on very good social work and/or family support.”

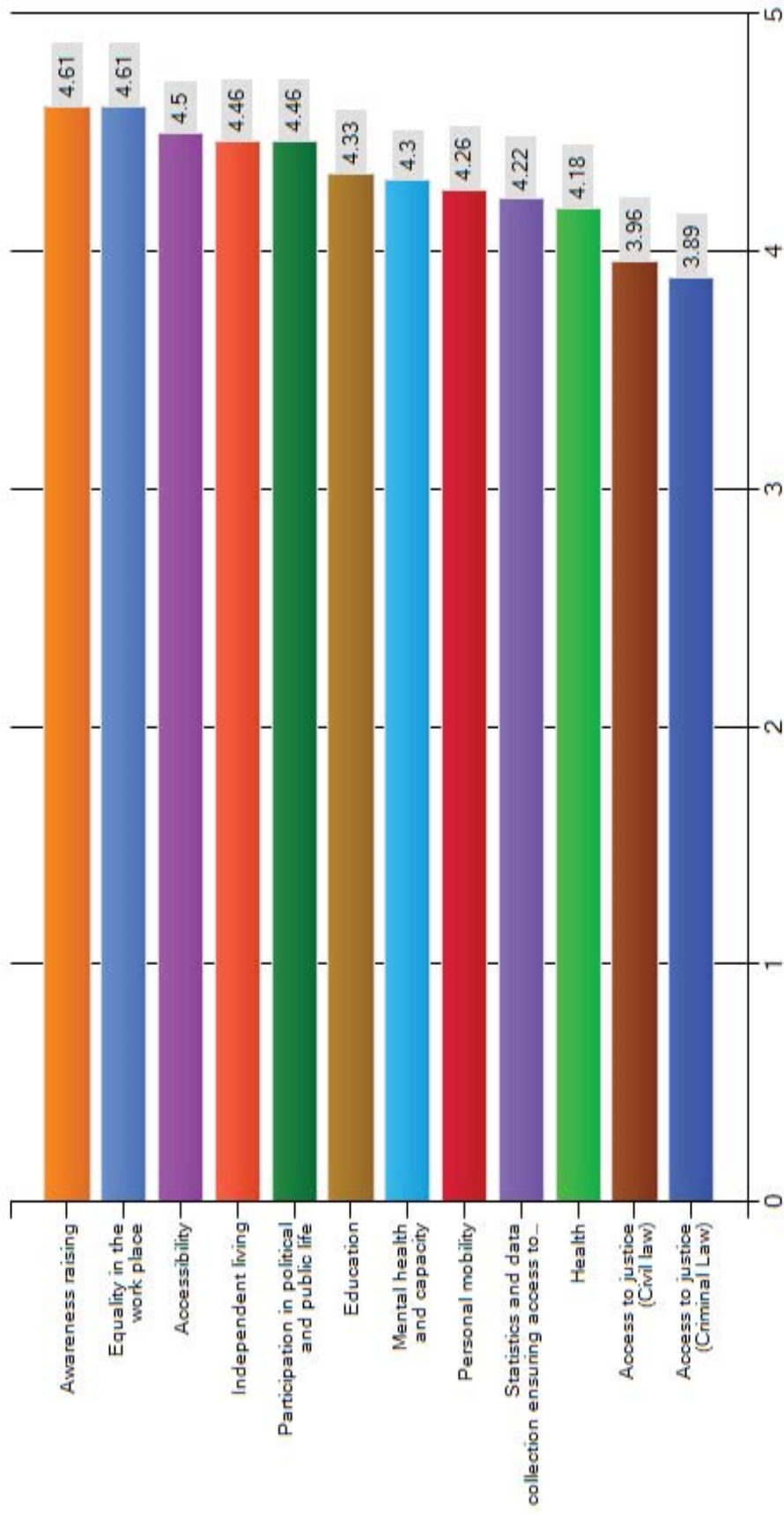
“Include voluntary context as being embraced with all disability issues.”

“Presentation and search for information, including digital access.”

“Discrimination in terms of media presentation.”

Figure 1: The average response rating for the key areas in Question 12

These are some of the areas suggested as having a gap between policy and programmes and the requirements of the UNCRPD. Do you agree? Please rate your agreement with each of these areas below from 5 to 1, with (5) being areas with which you would very much agree and (1) being areas with which you very much disagree. There is a text box at the bottom of the question for you to write in any additional area which you believe is critical. Please indicate your rating being the additional area.



The data contained in Table 13 and displayed in Chart 1 indicates that respondents viewed that gaps in policies and programmes were greatest in the areas of:

1. Awareness raising;
2. Equality in the work place;
3. Accessibility;
4. Independent living and participation in political and public life.

A comparison was undertaken between respondents who indicated that they had a disability and those who had not. The findings are summarised in Table 14 below.

Table 14: Top rated three key areas compared to declared disability (numbers in brackets indicate the rating by the other group)

Declared disability n=10	Average rating	Other Respondents n=18	
Awareness Raising	4.9 (4.44)	Participation in political and public life	4.67 (4.1)
Independent Living	4.6 (4.39)	Equality in the work place	4.61 (4.6)
Equality in the workplace	4.6 (4.61)	Accessibility	4.56 (4.4)
Personal mobility	4.4 (4.17)	Mental health and capacity	4.47 (4)
Education	4.4 (4.29)	Awareness Raising	4.44 (4.9)
Accessibility	4.4 (4.56)	Independent Living	4.39 (4.6)
Statistics and data collection	4.4 (4.12)		

It was noted that awareness raising is rated as a more important gap in policy by disabled people than non disabled people and participation is reported as being a more important gap to non disabled people (the vast majority of whom in this sample (96.1% - n=25) were government or voluntary sector representatives and elected officials). Accessible statistics and data are the joint fourth key gap area for disabled people whereas it is rated as tenth by

the non disabled group. Whether this reflects the experiences of disabled people is unknown and this will be explored further in the focus groups.

Significance testing was not carried out due to the small sample sizes involved and any conclusions are areas which will be explored further in the focus groups.

While not directly comparable due to the different methods used, the results from the open question at Question 10 (which addresses the main gaps between public policy and programmes in Northern Ireland) and the rating question, Question 12 which again addresses the policy gaps, have been put together in Table 15 to give an impression of the importance of each area.

Table 15: Results from the open question analysis of Question 10, ‘What are the three main gaps between public policy and programmes in Northern Ireland and the requirements of people with disabilities in Northern Ireland?’ and the rating scale in Question 12 ‘These are some of the areas suggested as having a gap between policy and programmes and the requirements of the UNCRPD. Do you agree?’

Note: = Equal rating			
Q10 Full Sample n=22	Q12 Full Sample n=28	Q12 Not disabled n=10	Q12 People with a disability n=18
Policy vs. Practice	Awareness Raising (=1st)	Participation in political and public life	Awareness Raising
Lack of Awareness	Equality in the Workplace (=1st)	Equality in the work place	Independent living
Employment	Accessibility	Accessibility	Equality in the workplace
Participation (=4th)	Independent living (=4th)	Mental health and capacity	Personal mobility (=4th)
Access (=4th)	Participation (=4th)	Awareness Raising	Education (=4th)
Education	Education	Independent Living	Accessibility (=4th)
			Statistics and data collection (=4th)

While the importance of each gap areas varies between the samples and questions there are some consistent areas notably **awareness raising, employment / equality in the work place, accessibility, participation.** These areas will be explored further in the focus groups.

8.4 Discussion and Conclusions

While caution must be taken due to the relatively small sample size and the limitations of the sample make up due to the self selecting properties of the participants, the scoping questionnaire did reveal areas of interest to explore further in the focus groups.

The introductory questions revealed that within the sample, disability was linked to an inability to take part in society on an equal basis with others and that knowledge of the UNCRPD is greater amongst disabled people than non disabled people.

The open questions whilst revealing a wide range of concerns and attitudes amongst disabled people and representatives revealed some key themes for further exploration in the focus groups.

Areas of negative attitudes by others, problems in relation to access and a lack of participation were cited as key barriers to disabled people fully participating in society in Northern Ireland.

One respondent commenting on these barriers wrote: "Access - including buildings, information and communication support. Attitudes - society's attitudes towards people with disabilities - lack of awareness of disability. People with disabilities are of the same value and worth the same as anyone else, therefore should be treated equally and fairly the same as everyone else." Another commenting on participation commented that there was a; "lack of effective consultation directly with disabled people".

When asked what key areas of public policy and programmes in Northern Ireland best enabled disabled people to fully participate in society, respondents cited effective legislation and policy, employment programmes and effective participation.

A respondent commented: "public representatives have to become fully engaged and represent disabled people as well as others. Policy formulation processes have to take into account the views and needs of disabled people and ensure that their needs are met. Governance and standard setting and monitoring processes have to take account of the views and needs of disabled people, and evaluation and accountability mechanisms have to be effective in safeguarding the position of disabled people".

Another commented that: "Employment, social and suitable effective, joint up programmes (including) transport initiatives can, if delivered and monitored correctly, be effective".

In response to the 'what are the three main gaps between public policy and programmes in Northern Ireland and the requirements of people with

disabilities in Northern Ireland', responses cited the disconnect between declared policies and those experienced by disabled people, the lack of awareness by service providers and in provisions for employment.

One respondent commented: "Public representatives, unless they happen to have personal experience, are unaware and unthinking about the existence and needs of people with disabilities. Policy formulators likewise: and they set the targets. Service deliverers are target fixated, and so don't see or listen to the needs of the disabled people under their noses: even if they do, the target, not the person, comes first. People with disabilities (especially permanent ones) are not seen, or listened to. So they don't exist as far as policies and programmes are concerned".

Another respondent commented: "lack of commitment from the leaders of public sector organisations to make it a priority that information and services are delivered in ways that are appropriate to people with disabilities. - good strategies but challenges to get them implemented and on the ground".

When respondents were asked 'what were the most important changes they would like to see to public policy and programmes to remove or reduce these gaps', it was commented that making policies work, effective participation and changing attitudes were required.

A respondent recommended: "monitoring progress on affirmative action programmes". Another commented that what was required was to: 1. "harness the experience and expertise of organisations advocating for those living with disabilities ("listen to us/use us!") ask) 2. Raise awareness and improve understanding of disabilities and their impact among public representatives, professionals and administrators and improve the policies, and services delivered. (To) 'improve your knowledge/ service delivery,' ask. 3. Develop the systems and provide the resources to enable participation of organisations representing disabled people in ensuring the effective and efficient treatment, care and support of those living with disabilities (An "involve us" and maybe even a "fund us"/" fund through us" ask)".

An examination of all comments made to any of the open questions revealed that four main themes emerged. These were;

- Awareness of the needs and requirements of disabled people and society attitudes towards them (52 comments),
- Legislation and policy including the effective implementation and monitoring of policy (51 comments),
- Accessibility including access to information (34 comments),
- Effective participation (33 comments).

These themes were explored further in the focus groups in the next phase of the study.

8.5 List of responses to the open questions (Questions 8 to 11)

Question 8:

Table 16: What do you think are the three key barriers to disabled people fully participating in society in Northern Ireland.

Responses

- The stigma associated with disability: people (especially those with power) are embarrassed by disability and want to deny its existence.
- The physical difficulties (travel etc) associated with participation, and the mental barriers- "Does he take sugar?" The fact that many disabilities are mental ones - people with impaired cognitive functions may not be able to understand what is going on. I'm not sure what the answer is here - carers have to be part of the picture
- Legislation and policy that is put in place then ignored or not (transferred) to front-line providers. Hopefully the UNCRPD being monitored may help;
Attitudes: no matter what, people do not see you as equal therefore you are actively de-skilled socially;
Education: equal access is not needs led but resource led. This starts the downward spiral in equality - less chance of employment you live on benefits there is no way out of the poverty trap! Nowadays you are scum, being on benefit (portrayal in the media) Being on benefit and having no chance of employment, where does that place disabled people?
- Young children being able to access mainstream education so that they can gain an education the same as the rest of their peers and be able to be employed so that they can have the same standard of living as everyone else;
Exclusion of disabled people so they are marginalised from society i.e. community groups do not accommodate disabled people. This could be because they are not aware of how to include people with disabilities in their activities, so therefore disabled people's self esteem and confidence is lower than what it should be;
Lack of awareness from the general public regarding stereotypes through the media and assuming that a one case scenario fits all! Not understanding that there can be varying degrees of certain disabilities and furthermore that certain disabilities can be hidden.
- Attitudes; lack of inclusive provision;
- Lack of effective consultation directly with disabled people.
- Lack of awareness of disability in the general public; employment [issues];[lack of] Interpreters at social events.

- I am a carer and look after someone who is disabled (in a wheelchair) and have had experience of a barrier as I was with the disabled person at the time. Translink refused the disabled person I was with access onto their bus as people who had prams were in the area that clearly states for elderly and disabled people. It also states that any passenger who is not disabled or elderly may be asked to vacate the area to allow disabled or elderly on. On this particular day, myself and the person I was looking after who was in a wheelchair (were) denied access. The bus driver did ask the person to move but he wouldn't and the bus driver said we would have to wait on the next bus. When the next bus came the same thing happened people with prams in the disabled area and we were denied access and had to wait on a third bus!! If it clearly states that the designated area on the bus is for disabled or elderly then that should be the case and if people with prams don't move they should be asked to leave the bus or be fined. Translink's answer to this situation was that the bus driver can only ask the people with prams to move if they refuse he can't make them. My answer to this is then why have an area specifically for elderly and disabled if anyone can use it and disabled people are refused access.
- Availability of accessible public transport; ability to access paid employment; misunderstanding of the needs of individuals.
- Ignorance; fear; and finance.
- Employment; health and social activities.
- Information to access services;
Comprehensive Spending Review / Budget cuts;
Lack of direct engagement with children and young people with disabilities and their parents/carers.
- Incentives and sanctions for organisations and service providers to provide accessibility;
Negative public attitudes to disability that exasperate disabled peoples own psychological barriers
- An assumption that people with communication disability are covered by current legislation; a complete lack of understanding of the unique needs of people with communication disabilities; a lack of training in communication disability
- Physical barriers, particularly for those living in rural communities;
Lack of opportunities for employment;
Lack of opportunities for meaningful participation in Society (need to go beyond the requirement to make reasonable adjustments, may need to change how we do our business).

- Accessibility - both physical and attitudinal; participation - in public life and cultural activities;
Education and employment - fewer qualifications leading to few / poor job opportunities.
- Ignorance of professionals;
Too much of a paper trail promising the world and delivering nothing;
No networking between professionals and disabled individuals. No sharing of information.
- Complexity of legislation; connectivity; education.
- Having their voices heard; being treated as an equal; fully accepted in society.
- Access; health; employment.
- Accessibility - being able to go places and not be judged as an inconvenience by other users;
Education-lifelong learning - as a mother of a young son with severe learning disabilities I am aware that when he leaves school at 19, unless things change significantly in the intervening years he will have very few opportunities for lifelong learning which are appropriate to his needs. Sadly the status quo seems to be that there is what there is, politicians are sympathetic but lack the drive to challenge the system and put proper structures and opportunities in place for young people with severe learning disabilities to live a fully inclusive and independent life.
- Depends on the nature of the disability
- I consider obtaining and maintaining employment to be one of the main barriers to disabled people participating fully in Northern Irish society.
I also consider negative attitudes and behaviours towards disabled people limit social participation. This next barrier may or may not be temporary, however, I consider, the economic climate to be socially, economically and physically limiting for disabled people.
- Environmental barriers - access etc;
Still too much emphasis put on the medical model of disability as opposed to the social model of disability and because of this most government schemes only work for people who fit neatly into the stereotypical boxes of disability. Things look good on paper but quite often when you try to apply them to reality you come up against a barrier relating to the benefits trap or some sort of choice trap. So therefore quite often there is a barrier to rights that exists even with schemes trying to fix this because they cannot be tailored to each individual circumstance;
Attitude and perception - stereotypical views are hard to change.

- Access - including buildings;
Information and communication support;
Attitudes - society's attitudes towards people with disabilities - lack of awareness of disability. People with disabilities are of the same value and worth the same as anyone else, therefore should be treated equally and fairly the same as everyone else
- Attitudes in society in general; lack of leadership; lack of participation in either the media or politics of people with disabilities.
- The following is based on some of the feedback received by HSC organisations when consulting on our Disability Action Plans and Equality Action Plans. Actions that will start to tackle these issues have been included in HSC Trust Disability Action plans and also in our Equality Action plans:
Lack of awareness on the part of public bodies as to what the support needs are to ensure that people with disabilities can participate fully e.g. accessible formats, easy read documents, making sure that loop systems are available, that they are working and that staff know how to work them;
Lack of leadership that directs staff to make sure that information sent out by health staff is in accessible formats e.g. appointment letters can be read by people with visual impairments, that people with hearing impairment aren't expected to phone in to confirm or change an appointment;
Need to look at feedback and complaints processes to ensure that people with disabilities have confidence in the system to give their views;
Need to look at how we recruit people for posts within HSC, how we support people to work as volunteers or on work placements;
HSC organisations need to monitor who are on our boards, partnerships, user groups etc - and identify how many are people with disabilities;
Need to develop effective staff training.
- Attitudes; legislation; resources.
- Obtaining employment in the first instance and retaining employment where a disability develops;
Lack of information regarding rights and available services;
Lack of an identified strong spokesperson on the rights and interests of disabled people at local government level.

Question 9:

What are the three key areas of public policy and programmes in Northern Ireland which best enable disabled people to fully participate in society?

Responses

- Public representatives have to become fully engaged and represent disabled people as well as others. Policy formulation processes have to take into account the views and needs of disabled people and ensure that their needs are met. Governance and standard setting and monitoring processes have to take account of the views and needs of disabled people, and evaluation and accountability mechanisms have to be effective in safeguarding the position of disabled people.
- Although Disability Action is accepted by Stormont as “the voice of disabled people”, you cannot advocate for any group of people unless your core funding is independent. My personal view: I feel they do not let disabled people advocate for themselves or encourage people to “speak out”;
Access has improved since the DDA but still early days.
- Employment, social inclusion, social development(in all its aspects)
- Don't know
- Disability Action Plans; Awareness Training for all staff on the needs of disabled people; Meaningful and inclusive consultation.
- Universal suffrage; DDA grants for physical adaptations / training.
- Equality as set out in the Bamford review; human rights as set out in the Convention; Disability Rights as set out in the Disability Discrimination Act
- Accessibility; education; employment; Independent living
- Section 75, DDA and DDO statutory duties on public authorities
- Improved accessibility through the public transport network; Positive action/Disability Action programmes which reach out to people with disabilities i.e. work placement opportunities and associated mainstreaming and inclusion policies
- Access to work; accessible high quality education; adequate health provision and independent living
- Accessible information; disability awareness training for staff; partnership working
- 1. Education 2. Work 3. Accessibility
- Disability Discrimination Act; UN Convention on the Rights of People with Disabilities UN Convention on the Rights of Children.
- The newly available mechanism, shared by the ECNI and HRC

- This is a difficult question to answer in full, however, in terms of an estimated guess, employment, social and suitable effective, joined up programmes, transport initiatives can, if delivered and monitored correctly be effective.
- Access to work is great if you can do without housing benefit for example if you live at home or don't require supported housing but unfortunately it does not suit every situation. Regardless of your suitability to work if you need to live in supported housing you can't really work unless you count supported employment which quite frankly although it does work for some after getting a degree and a post grad diploma in management I would find this degrading. In my eyes it is a way for the government to make statistics look good. Supporting people is a great scheme however it has very tight restrictions as to what it can be used for and very minimal hours per person already and it is set to become more limited
- Don't know
- I am not disabled so I don't really think it is my place to comment.
- Developing information in accessible formats; monitoring who is getting involved on our partnerships/boards etc; increasing the potential for people with disabilities to access employment. To ensure that people with disabilities are working at all levels of our organisations and receive the same opportunities for promotion etc.
- Disability Discrimination Act; access to work and workability programmes; special education needs policy.

Question 10:

What are the three main gaps between public policy and programmes in Northern Ireland and the requirements of people with disabilities in Northern Ireland?

Responses

- Public representatives, unless they happen to have personal experience, are unaware and unthinking about the existence and needs of people with disabilities. Policy formulators likewise: and they set the targets. Service deliverers are target fixated, and so don't see or listen to the needs of the disabled people under their noses: even if they do, the target, not the person, comes first. People with disabilities (especially permanent ones) are not seen, or listened to. So they don't exist as far as policies and programmes are concerned.
- Public policy refers to community care as 'Needs Led' yet home help policy radically changes and assistance that was given domestically is no longer provided. If a disability prevented someone from keeping the home hygienically clean suddenly the policy changes - can they suddenly cope or do they live unhygienic and susceptible to infection? Equality Therapies: ...no provision [for identified needs]- [e.g.] speech therapy, a basic method of communication that is afforded to a few. Leisure Centres had (not presently) 'passport to fitness'. If a person's medical condition could be improved by professional support at a gym they paid reduced access. If a disabled person could maintain their physical movement by professional support at a gym they had to pay full price
- Lack of understanding and acceptance of issues by public authorities; Lack of delivery on mitigation measures and the DDO duties; lack of acceptance of the importance of the Convention rights
- Awareness; Statistics; Participation.
- Whilst access to shops is mostly easy enough for people with a disability especially wheelchairs to get into. The shops pack goods for sale on the floor, this causes the aisles to be narrower. It's like an obstacle course to get around if you are in a wheelchair. I think on a tourism level not everyone with a disability can go on holiday in this country. It all depends on how disabled you are. e.g. someone who can't walk or stand cannot go to a hotel to stay as there wouldn't be a hoist to help the carer to move the disabled person from bed to toilet etc. I take the person I look after to Blackpool where the hotel we use has everything any disabled person needs whatever their need is. I would prefer to stay at home in N. Ireland and go on holiday but there just aren't the facilities. I think if this was to change then there would be more money generated into tourism in this country. Public transport needs to be

looked at as I said before about Translink. I think NI Railways don't always have a disabled carriage on the train. I think you have to tell them you're travelling with someone in a wheelchair - can't just go to the station on a whim and decide to get on a train because there would be more than likely no disabled carriage on the train.

- The idea that changes and service improvements cost money
- Enforcement; funding; reality checking - audit actualities not aspirational policies
- Enabling people with a disability to lead a full and active life; supporting disabled people at the workplace; encouraging disabled people to form personal relationships.
- Access to appropriate education, employment, training; lack of implementation of strategies; lack of co-ordination between NI departments in delivering services.
- More effective co-ordination and joined up approach to the implementation of policy
- People with communication disabilities are not included in consultations - they are unable to communicate. They are the hidden disability. Public policy does not recognise communication disability as a disability in its own right. There are no reasonable adjustments made for people with communication disability
- The assumption that you (public policy-makers) know what the needs are rather than talking directly to people with disabilities. Public policy is over complicated and not communicated in a user friendly manner. The assumption that all people with disabilities are the same i.e. not
- recognising within the deaf community the range of needs - need to look at the person not the disability.
- Access to work; accessible high quality education; adequate health provision and independent living
- Changing attitudes; benefits trap; resourcing and funding
- Whilst DDA is welcome and has resulted in significant changes in accessibility for people with disabilities-unfortunately when you are in a wheelchair or in a major buggy, as is my son, things are not seamless - things take longer. Moving around in busy areas like shopping centres is a nightmare. Still feel like a poor relation as you are shown in by the back door all too often. UNCRPD - I am really hoping to challenge the State Party on a number of Articles which relate to Post 19 Transition: Article 5 Equality and non discrimination -the current lack of opportunities at Post 19 discriminate against young people with severe learning disabilities as the opportunities that are available are inappropriate or unsuitable therefore there is no ongoing lifelong learning. Article 8 Social inclusion and elimination of poverty - in the

real world we know that if we don't work to support ourselves and our families we can be excluded from many aspects of society as we do not have the resources to enable us to participate. Disabled people are more likely to live in poverty than anyone else in society. Article 9 Accessibility; Article 20 Education - opportunity for lifelong learning; Article 27 Work & employment

- No provision for breaches in proper conduct with disability within a voluntary context. Definition of disability
- Need for strong professional knowledge base at all levels. Need for an informal advisory/advocacy service there, specifically to guide and advise disabled people if they seek to challenge an organisation/individual. Is there a travel policy for disabled people in terms of a break in the travel chain system such as a train breakdown? In other words what does a wheelchair user do if passengers need to disembark?
- There is greater equality within education, but this needs to be matched in all government programmes and the benefit system needs looked at to reflect the standard of education disabled people are obtaining as the benefit trap can stop disabled people in certain circumstances going into employment.
- Government not including or involving people with disabilities - finding out the needs of people with disabilities and what would make life better for people with disabilities.
- I am not disabled so I don't really think it is my place to comment.
- Lack of commitment from the leaders of public sector organisations to make it a priority that information and services are delivered in ways that are appropriate to people with disabilities. There are good strategies but there are challenges to get them implemented and on the ground.
- Hate crime legislation; enforcement of mediation programmes; evidence of discrimination at interviews/applications for work; vagueness of reasonable adjustments criteria of DDA.

Question 11:

What are the most important changes to public policy and programmes you would like to see happen to reduce or remove these gaps?

Responses

- 1. Harness the experience and expertise of organisations advocating for those living with disabilities (“listen to us/use us!” ask) 2. Raise awareness and improve understanding of disabilities and their impact among public representatives, professionals and administrators and improve the policies, and services delivered” (An “improve your knowledge/ service delivery” ask) 3. Develop the systems and provide the resources to enable participation of organisations representing disabled people in ensuring the effective and efficient treatment, care and support of those living with disabilities (An “involve us” and maybe even a “fund us”/“ fund through us” ask).
- Policy cannot change attitudes; Section 75 and DDA were to help people gain equal access to employment; policy is limited. There is policy to encourage disabled people into public office. The right attitude but unless the foundations are in place education that is a difficult task unless with an acquired disability.
- 1. The right to mainstream education. 2. Awareness among the general public. 3. Inclusion of disabled people in community activities.
- Focus on equality training and staff development on disability issues within the public sector; focus on impactful actions as part of DDO duties; focus on Convention and rights based training.
- Talk to disabled people.
- Public transport should be accessible for disabled people. There should be a designated area for people with disabilities, and their carers or the elderly that no one else can use. Tourism: hotels, etc should be looked at to make them up to date with across the pond (Scotland, England, etc) so that there are places to stay no matter what your disability.
- More public awareness of the value and cost of reasonable adjustments in public services. The valuable contribution that engagement with people with a disability makes to policy development.
- Change DDA so individual need not bring case but a body corporate can Watchdog with teeth Compulsory disability equality training in schools at age 5, 9, 12, 15.
- More resources to be provided, particularly for learning disability services, to enable these changes to happen.
- Increased engagement with disabled people and their families/carers. More joined up working on local policies.
- Monitoring progress on affirmative action programmes.

- Communication disability must be recognised in legislation.
- Greater employment opportunities, the more integrated people are the more barriers are removed. Creation of one-stop shop - more multi agency working.
- An improvement in education provision and the quality of provision to improve job prospects. Improvement in access to work - both in government provisions and employer attitudes to disabled people. Improved independent living arrangements.
- Meaningful engagement with the disability sector; more strategic engagement from the sector - collaborative working; joined-up approach from the public sector.
- Acceptance
- I would like to see accessibility as a real solution to the needs of people with disabilities not just tokenism. I would like to see government departments linking up to make a co-ordinated effort to resolve the issues of Post 19 Transition-looking at alternative options to FE colleges - inappropriate and unsuitable for young people requiring a lot of support. Work and employment ensuring that young people with [severe learning disabilities] SLDs find meaningful and rewarding work experiences suited to their needs it can be a very powerful learning experience for the workplace as a whole.
- Day centres - impossible to be catered for there as someone has to die to enable a young person to get a place. There is little stimulated activity to ensure lifelong learning. All the skills and independence they achieved at school is quickly lost within an environment in which the needs of the older residents are catered for and the mix of older and younger people doesn't quite work. Government need to be looking at alternative models of caretaking to those in Scandinavian countries, whereby another building for the young people is placed near to the school environment wherein they can continue to strive towards independent living within a supportive environment until 30-35 years. If we acknowledge that it takes these younger people many years to accomplish things that the rest of society take for granted why do we then assume that they will be able to cope with being thrown out of the only environment they have known to face the challenges of a hostile environment at the same time as young people who have studied for some years to acquire university places or have acquired the skills to move into employment- it's hardly a level playing field. Unfortunately for many families caring for a young person with SLD's Post 19 transition becomes a time when the family as a whole descends into poverty as parents cannot continue to work because of their caring responsibilities. It's a vicious circle.

- People operating within voluntary context to be included within the reach of all issues, to protect people with disabilities.
- Transparency, consultation and promotion of access to policy and programmes.
- I would love to see the benefit system getting updated to reflect the changing needs, wants and desires of today's disabled community.
- Involve people with disabilities - listen to them!
- More recognition of people's needs by those responsible for running the country.
- Increased encouragement to CEOs of organisations to provide leadership.

9. Appendix 2: Results from the IMNI conference workshop, 'Independent Mechanism research – priorities for public policy and programmes – Your views?'

Originally the 39 registered participants for this workshop had been split into five groups each with a facilitator, however inclement weather reduced attendance and there was an imposed last minute seating arrangement change. On the day the 28 attending participants from the State and voluntary sector and people with disabilities were divided randomly into 4 focus groups. Groups 1 and 2 answered the same question and groups 3 and 4 answered different questions as detailed below.

Staff: 4 Disability Action facilitators. ECNI observers also present.

9.1 Results from Group 1

Question to Group 1 and 2 - What do you think are the three main gaps between the policies and programmes in Northern Ireland and the requirements of the UNCRPD?

Ranked Priorities

- i. **Awareness raising** – Most important – lack of awareness – government and public policy makers
- ii. **Accessibility** – buildings / transport network not there for disabled people
- iii. **Employment** – recruitment and support
- iv. **Participation** in public life

Discussion

- Lack of government awareness of UNCRPD (onus on disabled person).
- Lack of general awareness (by public) and no drive to raise awareness.
- Guidance from government on the requirements of the UNCRPD in order that policy makers can review policies and any gaps.
- Legislative coverage - are the 1 in 5 disabled people covered by existing legislation (any gaps?)
- Need to match statistics to policy areas and awareness of what currently exists
- Helpful/important to know number of disabled people in employment (feeling statistics are weak or not well known)

- Feeling of 'hidden' discrimination in employment.
- Barriers to employment
 - Qualification requirements equal status for alternative qualifications.
 - Previous experience (impacted by discrimination)
 - More 'hazardous' employment pathways
- The DDO in public life is too limited, the duties are not sufficient to deliver meaningful change – a few poster or positions. Meaningful and comprehensive schemes and plans are required
- Effective consultations with people with disabilities

9.2 Results from Group 2

Question to Group 1 and 2 - What do you think are the three main gaps between the policies and programmes in Northern Ireland and the requirements of the UNCRPD?

Ranked Priorities

- Awareness raising** – leaders / public etc and the impact
- Participation in public life.** Failure to consult with persons with disabilities (especially with children and young people)
- Lack of understanding that the UNCRPD is a legal document.**

Discussion

- Failure to consult with young people
Gap – participation with children and young people with disabilities can give shape to their whole life if consulted!
People with disabilities- INCLUDE children with disabilities
 - Awareness raising – leaders / public etc and the impact of the convention
 - Lack of recognition of the legal force of the convention – we should all be using it! It's a legal instrument.
 - Need to match statistics to relevant areas.
 - Gaps in employment especially in relation to recruitment and support.

- Participation in political / public life at communication support, to enable people with disabilities to participate in the way programmes / policies are drawn up.
- No one strong voice?
- Awareness raising – how to use a document like this! That’s not generally done. The human rights of people with disabilities – targeted at different levels
- Getting people ‘switched on’ and changing attitudes
- Raising awareness of our leaders – more people with disabilities within the assembly.
- Not one policy applies to all – one policy will have gaps for others
- Educating children with disabilities within different schools - is that within a policy?

9.3 Results from Group 3

Question - What are the three key barriers to people with disabilities fully participating in society in Northern Ireland?

Ranked Priorities

1. Attitudes and awareness

- a. Confidence
- b. Prejudice/bias
- c. Ignorance and fear

2. Access to

- Information
- Privacy and sharing
- Reasonable adjustments
- Formatting
- Physical access

3. Income

- employment
- social security

9.4 Results from Group 4

Question - What policy or programme would you like to see introduced to help implement the UNCRPD in Northern Ireland?

Ranked Priorities

- i. **Awareness** (public / government / disabled people – age and disability convention applies to all)
- ii. **Access** (Buildings / transport – network not there for disabled people / health / benefits / employment)
- iii. **Education / Poverty** (Note from Group leader – Nicola O’Neill - not fully agreed by group) Transition from education to employment – forced down traditional routes – disabled people pigeon holed. Influenced into humanities).

Discussion

- Awareness raising using media
- Education - Employment
- If you have the capabilities to go into a profession you should be able to.
- Go into the profession you chose
- Why are people with disabilities under-employed?
- Poverty
 - Accessibility
 - Access to health
 - Buildings access
 - Transport –rural issues
 - Transport costs
 - Transport being personalised
 - Pro-active in relation to access
 - Access to benefits
- Housing
 - Lack of social housing
- Communication between services
- Definition on disabilities should include: ageing impairment, sight / hearing, social disabilities
- Implementation

10. Appendix 3: Results from the three scoping focus groups

10.1 Service user scoping focus group on 15 December 2010

Held in Disability Action in Belfast

Attendance: 8 service users

Staff: Simon McClenahan

Nicola O'Neill

Heather Logan

Following a brief overview presentation on the purpose of the research the group was asked two questions

10.1.1 Question 1: What are the key barriers to people with disabilities fully participating in society in Northern Ireland?

Focus group responses

Protection

Equal opportunities

Chance to air our views

Change for individuals

Removing barriers

Minimal universal standards

Social life

Housing

Employment

Political life

Freedom of speech

Freedom

Immigration, freedom to move

Protection from abuse, torture and bullying

Health

Transport (access)

Buildings

Access to information

Humanity from one to another

Independent living

Reasonable adjustments

Too much protection (from families)

Statistics missing on benefits

Benefits care - have to give up one benefit for another – system is problematic

- Awareness raising - "People's attitude towards disabled people; they are disabled, they are no good. However is there evidence of this?"
"Ignorance, assumptions, why are we not listened to"
- Employment – "Won't be taken on in employment – more likely to be off sick".
- Accessibility –
To information
Places / buildings
Policy makers
Access to Stormont
Signage
- Independent living – "Different getting loan because we are disabled, we are going to die quicker"
Can't get on property ladder
Direct payments

Top three barriers identified

Following a period of discussion the group decided that the top three barriers in descending order were:

- Participation: they were not being asked for their views, opinions and requirements;**
- Attitudes towards them from the public, employers and potential employers and from their families;**
- Accessibility including access to information.**

10.1.2 Question 2: How would you advise the Government to fully implement the UNCRPD in Northern Ireland?

Focus Group Responses

Awareness Raising

- Educate – awareness raising
- Raise awareness (transport timings, tactile markings on road) links to 'Ask me First'
- Need to let people know these issues are out there
- Need to hit attitudes
- Tackle political parties – need to challenge them, are they even aware of the UNCRPD?

- “Need to think bigger – national campaign – changes in schools and prisons etc – make people think, for example about access”.
- “School children need to be taught about disability in the curriculum”.
- “Attitudes from family, church and society with regards to disabled people and non disabled people”. Changing.
- “Some disabled people are not open to change”

Suggested Actions

- Needed to advertise nationally
- Schools
- Newspapers
- Target everyone
- Target some groups
- Very widespread campaign needed like the Clunk / Click campaign
- Public information films
- Advertise within PWD (persons with disabilities) groups to heighten awareness
- Active campaign by PWD (example: - Traffic lights in Derry)
- Need people to think about these issues to see the bigger picture

Consultation

- ‘Ask Me First’ campaign for children and young persons need this for PWD (persons with disabilities)
- Why not have a disability champion within government? – this is crucial for us. Disability Commissioner. Disability champion within each council
- Make sure they ask first.
- Currently policy is written first and then we are asked to comment – that is the wrong way round
- Assumptions are made
- Inclusion means include me

Monitoring

- Government / councils not being challenged
- Christmas lights in Derry – no disability access – raised awareness in Derry Council and pointed out problems
- We need facts and figures to challenge and to create policies

- Statistics not available and unable to gather the information, they (the State) had not thought about statistics for PWD
- Statistics need to be accessible (especially websites) in suitable formats and in one place. Like the children section in ARC
- No disability hate crime statistics on NISRA
- Article 31 has to be transparent, it is very important

Employment

- In adverts – need to add welcome for disabled people

Education

- Freedom of choice mainstream or not. Up to individual.
- No choice.
- “I can’t abide the word special, we are not special. It’s because society tells us we are special”.

Priorities For Change

Following a period of discussion the group decided that their 3 priorities for change were:

- i. Raise Awareness;**
- ii. Participation;**
- iii. Monitoring and Access to information and statistics.**

10.2 Representative (scoping) focus group on 10 January 2011

Held in Disability Action in Belfast

Attendance: 9 Representatives (NICEM, MS Society, RNID, Mencap, West Belfast Women’s Group, Carers UK, Belfast Carers, IMTAC, Victim Support) and 1 ECNI Observer

Staff: Simon McClenahan
Nicola O’Neill
Heather Logan

Following a brief overview presentation on the purpose of the research the group was asked two questions

10.2.1 Question 1: What are the key barriers to people with disabilities fully participating in society in Northern Ireland?

Focus group responses

- **Accessibility** – Deaf and hard of hearing - shop staff need more awareness training, loop systems made law. Physical access to shops and information in relation the policies of the shops.
- **Curriculum** – “information on disability is not normally given although this differs between schools. There is policy. Someone needs to do a school pack”
- **Not enough awareness at all levels** not just schools. Need public campaigns e.g. like the hard hitting ad for drink driving
- **Ignorance** – accessibility with the shops aisles. They think about ramps but not other things (awareness raising); Shop workers / everyone’s perception – raise awareness
- **Family** – attitudes
- **Prejudice** – access to justice (pan disability) attitudes of the courts, jury etc to disabled people
- **Legislation** – Who came up with it? Who designed it? – disabled people should be involved from the start.
- **Disability courses** - attendance - while in theory courses being held few staff have been through it e.g. PSNI
- **Waiting times for hospital appointments** – previous appointments, all about targets, people with learning disability not equal in care. Access to information in hospitals etc.
- **No recourse to public funds / health care** for disabled ethnic individual / groups
- **Rural areas** – difficulty in accessing services
- **Housing** – people with disabilities still in hospital – lack of accommodation
- **Right to independent living** - small pilot study in Northern Ireland – Southern Board - No policy
- **Cost** – lack of resources

Priorities for change

Following a period of discussion the group decided that the top three barriers in descending order were

- i. **Participation** – not being asked
- ii. **Accessibility to information about rights**
- iii. **Awareness raising** – lack of understanding / knowledge / awareness raising – communication needs

10.2.2. Question 2: How would you advise the Government to fully implement the UNCRPD in Northern Ireland?

Focus group responses

- **Participation** - Ask first – ‘the person with the disability knows what the disabled person needs’
- **Change attitudes** – State needs to do it. OFMdFM overarching responsibility. Top down strategy. Cross departments e.g. like Race champions – joined up working – multiple discrimination lines
- **Access to information** - Change attitudes in employment - people don’t know about the schemes. Knowledge of the schemes needed.
- **Training** - needed for all staff in relation to communication with disabled people.
- **Statistics** - everyone needs to know
- **Education** - in awareness raising everyone needs to know. Include MLAs (Chuck Feeney grants for representatives)
- **Legislation change** – written by people with disabilities
- **Disability Awareness** - training of frontline staff in transport - there is policy but how do you change things that aren’t working
- **Systems to monitor policy** – asking people who use the services
- **Participation** - more discussion groups.

Priorities for change

Following a period of discussion the group decided that the changes to fully implement the UNCRPD in descending order were:

- i. Participation;
- ii. Accessibility to information about rights;
- iii. Awareness raising.

10.2.3. Focus group evaluation (6 responses)

Positive

- Let us talk, able to highlight our views, very important
- Everyone had a chance to speak and voice their opinions. Enjoyed informative introduction summary.
- Kept to time
- Everything was suitable for us (disabled). Food and break times good, able to meet other people.
- Everything was OK
- Everyone was valued and listened to.
- Timings, participation and discussion

Negative

- Would have been helpful to know what thematic areas are being covered and on what dates.
- Comment
- Thematic areas were being identified in part by these focus groups. While dates were available and were indicated to the group - themes were not set at this point.

10.3 Representative scoping focus group held on Friday 14th January 2011

Held in Disability Action Belfast

Attendance: 8 Representatives (RNIB, CAJ, Guide Dogs NI, Cedar x 2, PSP, RNID, REAL) and 1 ECNI observer

Staff: Simon McClenahan
Nicola O'Neill

Following a brief overview presentation on the purpose of the research the group was asked two questions

10.3.1 Question 1: What are the key barriers to people with disabilities fully participating in society in Northern Ireland?

Responses

- Access to information - Inaccessible information. "Language used by government - Jargon –can be an issue, ask users first about language use and standards"

Key Barriers

Following a period of discussion the group identified the three key barriers:

1. **Lack of Participation (Ask First);**
2. **Lack of Awareness;**
3. **Lack of Accountability and monitoring.**

Comment "Everything we have said today is important"

10.3.2 Question 2: How would you advise the government to fully implement the UNCRPD in Northern Ireland?

Responses

- **Awareness** - Train government on the UNCRPD, make them fully aware it's a legal document.
Make the public aware
People with disabilities need to understand each other
Disabled people aren't only interested in disability issues!
Respect for the individual.
- **Access to Information** - Disseminating information and communication.
Access to government e.g. Stormont
Education and communication
- **Participation and inclusion** - "Support is essential from the top for example a disability champion in each government department".
More people with disabilities in public life.
"Disabled forum would be useful somewhere the government could consult".
"Government should speak to user forums, reference groups, there are different ways of doing it", etc meeting, web etc.
Government need to listen "we are not always listened too".
"A Disability Commissioner and advisory forum could give us the voice we lack at this time".
- **General** – "We as individuals and groups have to work with the convention"

Key areas for government action

Following a period of discussion the groups decided on the following three key areas:

- i. Awareness raising;
- ii. Participation;
- iii. Need a central focus, a disability commissioner to give us the voice we lack at this time.

10.3.3. Focus group evaluation (5 Responses)

Positive:

- Very good, down to earth. Informative yet informal. Hope to attend the other focus groups
- Very casual yet very informative. I will be attending the other focus groups
- Very well organised focus groups, facilitation very good and all comments valued
- Everyone had the chance to speak, polite control, easy to follow content, excellent handouts
- Very good, I enjoyed it

Negative:

- None made

11. Appendix 4: Results of the three thematic focus groups

11.1 First thematic focus group on the 19th January 2011 (Awareness raising)

Held in Disability Action in Belfast

Attendance: 14 representatives (Rainbow / Cara-friend, DARDNI, Cedar, Real, Disability Action, MS Society, RNID), persons with disabilities and an ECNI observer

Two Disability Action Staff: Simon McClenahan and Nicola O'Neill

On arrival the mixed group was separated randomly into two workshop groups. Following a joint overview presentation on Awareness Raising within the UNCRPD, the groups were asked the same questions.

11.1.1. Question 1: How would you raise awareness throughout

society (including at the family level), foster rights and dignity, combat stereotypes, prejudices and harmful practices; promote awareness of the capabilities and contributions of persons with Disabilities?

Responses

- **Family**

The importance of the family was stressed by participants and it was considered that this should be the "first point of action".

"Stigma around disability and family issues, for example, a single parent with disabled child so won't cope".

"Easiest way to bring to family is through child's education".

"Learning through life and work - the school choose (the subjects) and disability is rarely selected as a Section 75 option. Maybe a school's pack".

"Stigma of having a child with a disability - the parents are to blame".

"Parents of disabled children and disabled children are being excluded by being kept out of the social stream (clubs, parties etc), and there should be more awareness of this".

Influence through Ads, media – "more support of a person who acquires a disability or a partner becomes a carer or you become a burden".

Mentor – through a voluntary sector organisation

- **Religion**

“Beliefs have an impact on how disability is perceived. It was a sin – the person or parent of a disabled child did something wrong so (were) punish(ed) with disability. This may also affect some migrant groups”.

Faith communities – through pulpit or prayer mat. Participants considered that awareness raising through the church was a good way to change attitudes in certain communities.

- **Employment**

Employers do not believe you if your disability is not visible, hard to challenge employer. One participant commented that she had to show her operation scar to her employer.

Help from employers on pregnancy but not in relation to disability.

- **Education**

“Knowledge is power! – How do we educate disabled people on rights”?

“Awareness raising also applies to disabled people. (we should) deal with disabled people at the same time as (looking at awareness raising from) the top down”

“Raise awareness with schools, statutory bodies, scouts, (and) youth clubs”

A disabled person going into Health Trust offices –explaining why there is a need (for a scribe).

Training – it was best practice to have “disabled people giving the training as they had been through the experience”.

Through information to schools and colleges

How many disabled teachers are there? Lack of information – Education – Teacher training college.

Education – learning for life to include disability

- **Media**

Media – “State’s responsibility”.

Also use “new media especially for younger people e.g. facebook, twitter, websites. Have discussion on programmes such as Stephen Nolan or Spotlight”.

“BBC and other channels on TV use pretty disabled actors. No speech difficulties, disfigurements”

Banks – access – How do you change attitudes? They refused to appear on TV to discuss an access problem highlighted by a disabled person.

“Media needs to be involved, look at the success of the drink driving campaign. Any campaign should examine the difficulties and use the correct language and people – a person with a disability. The campaign should involve disabled people in the planning and creation of the campaign”.

- **Government / Stormont**

Participants commented that disabled people should be consulted at the start of any planning process to tell the State what is needed.

Problem stems from MLAs in Stormont – not putting foot down.

A representative commented that he had met with the OFMdfM committee who appeared to have little knowledge of the UNCRPD.

Another participant reported that they had spoken to eight MLAs and that not one of them knew about the Convention.

Participants reported confusion in government in that many officials they had dealt with believed that if they followed the disability duties that that would suffice for their duties under the Convention.

A question should be asked of the OFMdfM as to the information provided by them to MLAs on the UNCRPD

The OFMdfM should police the internet for accessibility

Department disability action plans should be changed to reflect the UNCRPD

There should be a coordinated campaign fed into by local ones.

Forums for disabled people should be set up in each department so that there is a voice inside.

Conflicting policies between departments, better coordination is required.

Commissioner / representative for disabled people

Assembly / Departments have a forum for disabled people or a participation network that they can come to.

Enforcement made law (disability legislation should become enforceable)

Disabled people becoming members of political parties

Access to information. Policies need reviewed e.g. accessible information.

Disabled people involved at the beginning (important because disabled people are not involved until later stages)

Stop bickering – if you don't agree don't release it.

- **Health**
The attitudes of staff in the Heath service was commented on by participants who though that staff treated the condition not the person
- **General**
Posters on walls to get the knowledge out
Focus group to organise information day to get message out – however not “our” responsibility!
Willingness to learn is a problem
A measure of public views now to benchmark attitudes is required.
Change attitudes in society
Access to advocates
Small micro issues difficult to change – listen, learn, understand, engage and implement.

11.2 Second thematic focus group on the 26th January 2011 (Participation in political and public life)

Held in Disability Action in Belfast

Attendance: 14 representatives (Cedar, Real, NICEM, MS Society, RNID, One Voice for Change, West Belfast Woman’s Group), persons with disabilities and an ECNI observer

Two Disability Action Staff: Simon McClenahan and Dara Toal

On arrival the mixed group was separated randomly into two workshop groups. Following a joint overview presentation on participation in political and public life within the UNCRPD the groups were separated by a sound and sight board and two groups were asked the same two questions.

11.2.1 Question 1:What are the barriers stopping your

participation in political and public life?

Focus group responses

- **General**
“The Barrier has just been set up” (in relation to screen erected to divide the room up during breakout sessions).
“The lack of funding is preventing groups participating”.
“Statistics are important”.

- **Accessibility including to information**

“Accessibility issues are preventing participation, especially access to buildings, to amenities such as accessible taxis, toilets and many other services”.

Access to Information / communication / advocacy

“In relation to political life what support should be in place: a car/driver, accessible transport, access (overall), accessible information / scribe etc.?”

One participant who was a political party member commented on the lack of access to ramps in his local office. A number of participants commented on the access restrictions into Stormont in that, there was no access though the heavy double inside nor through the front door adding that they had to access “in through the back door”. Another participant asked “how many offices are accessible?”

“Problems in access to transport to get to the venue / setup – layout in the venue. For example is it on the ground floor? Are there toilets? Are there wider automatic doors, a loop system and interpreters. Is information available in easy read, Braille, or large print, is there someone to scribe for you?”

“New builds should incorporate fully accessible facilities”.

Access to buildings.

“Leaflets not (immediately) available in alternate formats” i.e. large print. It was commented that large print is often confused with easy read by staff.

Physical access and time. “Extra time may be needed to allow a person with a disability to contribute fully to a discussion”.

“Websites not suitable for disabilities” e.g. those with sensory impairments or learning disabilities.

“Lack of disability access on websites”.

“Lack of access for deaf people, and people cannot act on their behalf”.

Costs involved are a barrier including transport and also concerns about the interaction with benefits.

Systems in Government are confusing for some disabled people (lack of knowledge of processes).

One disabled participant mentioned what they termed the ‘Annie principle’ in which constant contact with the holder of the information is necessary to get a question answered; otherwise it will fall to the bottom of the pile. This “contact by disabled people is often difficult

due to different issues, communication difficulties, health, and the inaccessibility of information and figures to formulate questions". Participants reported that many government employees did not realise this and did not allow further time for disabled people.

- **Awareness raising**

Basics – down to awareness, political parties are not aware, what percentage of disabled people make up the vote, one in five has disability – who votes, who are able to vote with the current difficulties, "listen to me, we have thoughts too!"

Lack of Government awareness.

Capacity building

More pro-active action needed on disability issues

Lack of respect for disabled people

Lack of awareness of disabled people (mindset)

(Disabled) viewed as second class citizen(s), gay (issues), sexism etc are dealt with, but not disabled.

Ignorance is a barrier. Lack of capacity - access to information is essential

Lack of knowledge about the UNCRPD and disability

- **Participation**

Parties – don't want to know you- only when they are seeking votes

Inclusion at all levels! – They (the State) should be including us from their own guidance but are not doing so.

Consulted at the beginning of processes and not at the very end – being asked after policy is written.

"Can get people to "listen" but they don't actually "hear."

No disability outreach person in political parties

Only refer to disabled people on disabled issues – not, for example on the environment

Consultation rather than participation.

Lack of action coming from consultations.

Lack of lobbying skills – disabled people must learn.

11.2.2 Question 2: What are your solutions?

- **Awareness Raising**

Attitudes / opinions/ mindset of people need changed “doesn’t matter what time it takes as long as they are changed”.

Public servants are there to serve the public – and demand the service you are entitled to.

“The ball is in your court” – it’s down to individual – don’t wait about, get on with it.”

Awareness raising in the media – twitter – web – schools – the government first and then non government parties (2nd).

- **Participation**

Involvement at all levels

“What Disability Action has done with this focus group is excellent, a group should be formed from this - progress would have to be made.”

Increase participation of disability people in political parties and contact from political parties with disabled people and groups.

Contact with politicians important.

Training and capacity building of disabled people especially with regard to lobbying skills and how to access information.

Political parties should have disability champions – separate from Equality Officers.

More focus groups and discussions.

Participants would join focus groups if they knew action was coming from it.

Consultation will grow once the State becomes more aware of UNCRPD and disabled people’s requirements.

More lobbying (education needed in government systems and lobbying).

Two way language.

Access into policy makers however they must realise that extra time may be needed - cancelled appointment due to medical issues.

Awareness of disability issues, transport, medical issues when organising consultations.

Organising body should pay transport costs to consultations and there should be extra help to attend.

There should be a disability working committee in Stormont and information should be fed into it.

Disabled people should be consulted in any matter (at early stage)

There should be consistent information and trouble shooting of any problems.

There will be hard to reach groups which may require the use of social media sites and the media.

- **Government**

Government should be more approachable.

Tick every single box - they should be commenting about the voting patterns of disabled people just like the young.

A Commissioner for persons with disabilities, however is there the money?

“There should be one contact point within each department but with a coordinating body overseeing this. Perhaps a participation network”.

- **Accessibility including information**

Signposts to information and advice are required to enable people with disabilities to fully participate.

- **Monitoring and Statistics**

Realistic / independent monitoring; Accountability

Article 33 – full implementation

11.3 Third thematic focus group workshop on the 18th February 2011, Article 9 and 21 ‘access to information’ and Article 31 on ‘statistics and data collection’

Held in Disability Action Belfast

Participants: 11 People (representatives (Victim Support, REAL, Cedar, One Voice for Change, RNID, North Belfast Women’s Group) and persons with disabilities) plus one ECNI observer.

Two Disability Action staff: Simon McClenahan
Nicola O’Neill

On arrival the mixed group was separated randomly into two workshop groups. Following a joint overview of Article 9 and 21 Access to information and Article 31 on Statistics and Data Collection by Disability Action staff, the groups were separated by a sound and sight board and the same two questions were posed to each group.

11.3.1 Question 1: What are the barriers stopping persons with disabilities getting access to information including statistics?

Focus group responses

Combined responses from the two focus groups

- **Websites**

Participants from the focus groups reported that they found some government websites inaccessible; problems were reported with the inability to change fonts, broken or incorrect links, no search boxes, and the inability to change colours. They commented that they believed that this was due to a lack of knowledge by the website designers, or that people with disabilities had not been asked to test the sites.

Participants also reported that some websites did not work with the technologies used by disabled people.

Phone numbers given on websites did not work.

Incorrect information was given in websites. One participant reported that an example of this was in relation to access into leisure centres in which some reported that there was access whereas access was in fact difficult.

The lack of text phone numbers was mentioned by a number of participants.

Participants reported not receiving responses from website enquires. This was also reported for private entities especially in regard to the cancellation of services.

Accessibility requirements varied with the disability of the person.

Form filling on line was reported as a problem by participants as they could not resize forms.

It was commented that signposting was poor on websites and that there was little logic in their layout.

- **Statistics**

Participants commented that they had not realised the importance of statistics in relation to policy making and monitoring before the focus group discussions on the UNCRPD.

It was commented that capacity building is required for disabled people to fully take part in the monitoring process under the UNCRPD. (Note under Article 33(3))

It was reported that they did not know where to look for data and statistics and that there was little signposting. They reported statistics were hard to find.

A participant reported that statistics would not be comparable between GB and NI due to different systems being in operation (education and health)

One participant reported that he had tried to find out the number of amputees in Northern Ireland but that figures had not been available. When he made enquires by phone he had been asked by a member of staff, why he wanted to know.

The participants reported that they were unaware of schemes to have input into data collection.

- **Attitudes of staff**

Participants reported that the attitudes of staff towards disabled people were a primary barrier to them obtaining the information they required.

Staff did not give them the extra time they needed and many participants reported examples of staff putting phones down or asking why they wanted the information. Participants reported that this was reducing their ability to participate in society.

Participants also commented that the absence of accessible help lines was reducing their ability to access the service being offered.

A participant reported that people with learning difficulties were not gaining access to justice due to staff (or institutional) attitudes in relation to their capacity as witnesses.

Participants commented that negative attitudes towards disabled people were still entrenched at all levels.

- **Access to information**

A particular problem was reported by the RNID representative in that many government bodies, banks etc would not accept third parties contacting them on the telephone on behalf of a deaf or hard of hearing persons even after the reason were explained to the member of staff.

Access to forms – many participants reported that Easy Read forms to apply for services cannot be obtained. They reported that they found difficulty in accessing help to complete the forms.

One participant reported that while attending at a local clinic they were not informed by staff that there was not a lift for access to the clinics on the first floor and that they had to go elsewhere at additional expense. They commented that, "staff awareness in relation to the access requirements may have been at fault".

Two participants commented that there was a general lack of knowledge of the government systems or processes, who to contact and that they felt excluded. More information was generally required and that this should be supplied without jargon and in an accessible format.

Participants reported that there was little coordination between government departments in relation to the accessible information available.

Participants reported that people with disabilities were not being generally consulted in relation to the formats in which information was available (format included colour, layout, size and language)

Wheelchair users can pay 1.5 to 2 times normal fare to use taxis despite new taxi regulations. Are operators and disabled people aware of the regulations?

11.3.2. Question 2: How would you improve the situation?

- **Greater co-ordination**

Participants commented that disability groups need to cooperate and learn best practice from other NGOs and voluntary groups.

Government should have one person (with) overall (responsibility). There was general support for a Commissioner, although if overall responsibility remains with the Disability Unit of the OFMdfM then greater awareness raising of its identity, function and responsibilities is recommended.

Participants commented that greater government co-ordination is required and that information directly concerning disabled people should be centralised.

Participants recognised that disability is a diverse issue and responsibility crosses departments but commented that coordination is central.

Crucial to coordination is consultation with disabled people at an early stage and at the action plan stage.

It was commented that there should be considered planning and coordination and not knee jerk reactions and quick fixes.

- **Government action**

Participants commented that government must implement the UNCRPD especially article 33(3).

Participants reported that the current divided politics in Northern Ireland may result in a lack of political will to implement the UNCRPD.

Planning must be flexible and not written in stone. A participant giving an example of this reported that a disability action plan for 2008-2011 on the assembly website made no reference to the UNCRPD. When this was questioned by the participant it was commented that the UNCRPD had come in to effect after the disability action plan.

Participants commented that the monitoring and implementation of the DDA including the disability duties was problematic and it was crucial that stricter monitoring was undertaken of the implementation of the UNCRPD

Participants commented on awareness raising by government in relation to the supply of information not only amongst government employees but also with disabled people was needed. It was commented that "signposts to information should be available in places people with disabilities frequent, including doctors' surgeries, hairdressers, post offices and supermarkets."

It was commented that government should look at examples of best practice elsewhere. Scotland was given as an example in relation to the setting of standards for accessible communication i.e. easy read.

Comment made that the appropriate adult scheme for alleged perpetrators of crime should be extended to cover the victims or witnesses of crime.

A participant commented that, "research information on disability does not appear to be reaching policy makers."

- **Access to information**

Skills in relation to accessing government information and making applications online should be incorporated into 'learning for work and life' taught in schools.

Participants commented that there was a need for greater advocacy support.

Participants commented that many disabled people have no access to academic reports which are on pay to see services. An abstract reporting service such as that supplied by ARC on children and young person's research would be useful.

It was reported that an 'Easy Read version of statistics would be useful'.

In relation to front line staff attitudes towards disabled people, it was commented that more help and patience with disabled people by staff would assist people access information, as would an acknowledgement of the right of disabled people to access this data.

The use of Facebook and other social sites to receive and give information was suggested as good practice by the participants, with the North Down PSNI site being cited as good practice. Some concern was also expressed about the misuse of the system and monitoring was advised.

Participants recommended more proactive engagement of disabled people by NISRA.

Participants reported problems with understanding information in current formats and recommended increased use of easy read and plain English versions.

Participants recommended the placement of UNCRPD information in places frequented by disabled people including social areas such clinics, post offices and supermarkets.

Disabled people should be involved in research and data collection.

- **Websites**

One fully accessible centralised website was preferred by participants.

Disabled people should be involved in the testing and development of Government websites.

Voluntary sector to lead research / audits on web-sites however funding will be required.

Equality Commission

FOR NORTHERN IRELAND



CRPD

Independent Mechanism
for Northern Ireland

Promote | Protect | Monitor



NORTHERN
IRELAND
HUMAN
RIGHTS
COMMISSION

The Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission have been jointly designated, Under Article 33(2) of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), as the Independent Mechanism for Northern Ireland, to **“promote, protect and monitor implementation”** of the UNCRPD.

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