RESPONSE TO THE CONSULTATION ON THE FUTURE OF ADULT CARE AND SUPPORT IN NORTHERN IRELAND

Summary

A. The Northern Ireland Human Rights Commission (the Commission) has prepared this advice to assist the Department of Health, Social Services and Public Safety (the Department) in its reform process of the adult care and support system. The Commission welcomes the founding principles identified by the Department. While human rights are understood as one of the core principles, the Commission recalls that human rights encompass independence, dignity and respect, equality and diversity, as well as safeguarding, sustainability and affordability. In this sense, human rights are overarching and can serve as a basis to inform the Department of its obligations and facilitate a human rights based approach to reforming the care and support system.

B. The Commission recognises the complexity of the reform process and the range of human rights engaged in delivering physical, mental and social care. The Commission therefore advises that any future consultations, policies and laws incorporate a human rights based approach from the outset. It is paramount that the consultation and reform process ensure the effective participation of affected individuals. In particular, the Commission advises that the NI Executive take special consideration of the most vulnerable groups and that their views are adequately reflected in the Department’s future work.

C. The Commission notes that current adult social care is not only provided by the statutory sector, but also by the private and voluntary sector. The Commission recalls that the NI Executive has a duty to ensure all service providers respect and protect the human rights of beneficiaries. The Commission notes that the
human rights obligations articulated within the Human Rights Act 1998 also extend to the private and voluntary sector, where these provide services of a public nature.¹

D. The Commission welcomes the Department’s aim to ensure individuals can continue living independent, healthy, active and inclusive lives with the support of care and support provided. The Commission thereby notes the importance of considering the right to independent living and participation in the community. The reform further engages economic, social and cultural rights, which require care solutions to be available, accessible, adequate and of good quality for all on an equal basis.²

E. The Commission notes that the current reform proposals are in the early stages of development and raise cross-departmental issues. The Commission’s advice has therefore been developed in this context. The Commission would be pleased to provide specific advice on any particular aspect of the reform proposal and would welcome the opportunity to meet with policy makers for this purpose.

Introduction

1. The Commission pursuant to Section 69(3) of the Northern Ireland Act 1998 reviews the adequacy and effectiveness of law and practice relating to the protection of Human Rights. In accordance with this function the following statutory advice is submitted to the Department of Health, Social Services and Public Safety (the Department) in response to the consultation ‘Who Cares? Future of Adult Care and Support in Northern Ireland’ (the consultation document).

2. The Commission bases its position on the full range of internationally accepted human rights standards, including the European Convention on Human Rights as incorporated by the Human Rights Act 1998 and the treaty obligations of the Council of Europe and United Nations systems. The relevant international treaties in this context include:

   - The European Convention on Human Rights, 1950 (ECHR) [UK ratification 1951];
   - The International Labour Organisation Social Security (Minimum Standards) Convention, 1952 (ILO Minimum Standards) [UK ratification 1954];
   - The European Social Charter, 1961 [UK ratification 1962];

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¹ The Human Rights Act, s.6(3)(b).
² UN Committee on Economic, Social and Cultural Rights (CESCR), General Comment No. 6, The economic, social and cultural rights of older persons, 8 December 1995, at para 12.
European Code of Social Security, 1964 [UK ratification 1968];

The International Covenant on Civil and Political Rights, 1966 (ICCPR) [UK ratification 1976];

The International Convention on the Elimination of all Forms of Racial Discrimination, 1966 (ICERD) [UK ratification 1969]

The International Covenant on Economic, Social and Cultural Rights, 1966 (ICESCR) [UK ratification 1976];

The Convention on the Elimination of all Forms of Discrimination Against Women, 1979 (CEDAW) [UK ratification 1986];


3. The Northern Ireland Executive (NI Executive) is subject to the obligations contained within these international treaties by virtue of the United Kingdom’s ratification. The Commission recalls that Section 24(1) of the Northern Ireland Act 1998 requires that all Acts of the Department are compatible with the ECHR. In addition, Section 26 of the Act also requires compliance with international obligations. The Commission, therefore, advises that the Department scrutinise the proposed Strategy for full compliance with international human rights standards.

4. In addition to these treaty standards there exists a body of ‘soft law’ developed by the human rights bodies of the United Nations. These declarations and principles are non-binding but provide authoritative guidance in respect of specific topics. The relevant principles referred to in this context are:

- UN Principles for Older Persons, 1991;
- UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, 1991
- The Madrid International Plan of Action on Ageing, 2002

The Human Rights Normative Framework

5. The Commission highlights the NI Executive’s obligation to ensure the strategies adopted are in conformity with the treaties ratified by the United Kingdom and the Human Rights Act 1998 and the need for this procedure to incorporate a human rights based approach (HRBA).
A. Human Rights Based Approach

6. The Commission welcomes the Department’s identification of founding principles to underpin the future care system and inform individuals of their rights with regard to care and support. The Commission notes that, seen from a human rights perspective, those principles represent legal entitlements of service users, guaranteed to them on the basis their human rights. Human rights therefore embody all of the core principles identified and form the foundation of the care system. Recognising these core principles as human rights entitlements will facilitate the Department’s work in applying a HRBA to the reform process and guaranteeing a future care system, which respects, protects and promotes everyone’s human rights.

7. Final policies and legislation must comply with the UK’s binding human rights obligations, but so must also the processes by which they are developed and applied. A HRBA is not any more resource intensive than the current machinery of Government demands. However, adopting this approach will ensure that legal requirements are met and will also lead to better quality of outcomes for service users.

8. A HRBA in relation to adult care and support means that human rights norms and principles are integrated at all stages of the design, implementation, monitoring and evaluation of the consultation process and related policies and programmes.

9. A HRBA rests on the core human rights principles of i) universality and indivisibility of human rights; ii) equality and non-discrimination; iii) participation and inclusion, and iv) accountability and the Rule of Law.3

10. The lens adopted in a HRBA recognises the universality and indivisibility of human rights inherent to all persons. Placing individuals and their particular requirements at the centre, the HRBA ensures non-discrimination, equality and prioritisation of the most vulnerable and marginalised. It empowers people, facilitating their active participation in forming the laws and policies that impact their lives. At the same time, the HRBA increases the capacity of duty-bearers to recognise and respect those rights and

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respond accordingly, holding them accountable where they fall short of meeting their obligations.

11. The proposed reform of adult care and support engages various human rights. For instance, rights engaged in a care home context, will include the rights to health, housing, food, non-discrimination, independent living, as well as to private and family life. Additionally, the rights to life, integrity and not to be subjected to inhuman or degrading treatment may be engaged. Certain circumstances may also give rise to issues under the international conventions providing specific protection to a particular group, such as women, ethnic minorities or persons with disabilities.

12. The current language of the consultation document refers largely to the increasing needs and expectations of people with regard to social care and support services. Seen from the lens of a HRBA, however, it is clear that everyone has a legal entitlement to physical, mental and social health care they need. Adopting a HRBA would help translating needs into rights and identifying rights-holders, as well as the corresponding legal obligations that policymakers, legislators and providers of goods and services carry as duty-bearers.

13. The participatory element of the HRBA recognises people as key actors rather than passive recipients of charitable commodities and services. In this sense, the Commission notes that not only older persons but also disabled persons are stakeholders in the present reform process, which includes physical, mental and social care concerns. In consulting with these stakeholders, the Commission advises that special attention be paid to mobility and communication barriers that may exist with regard to certain groups.

14. The accountability element of a HRBA includes the need for setting measurable human rights indicators and collecting and disaggregating data on the protected grounds of discrimination. This allows for the identification of the potential impact of relevant laws, policies and practices and an early warning mechanism regarding possible violations, in particular with regard to marginalised and vulnerable groups. It also enables all actors to monitor and evaluate progress throughout the various stages of the reform process.

15. The Commission advises the Department to ensure the consultation process and the reform itself adopt a HRBA, taking into account the inter-dependency of the different rights engaged, the multitude of stakeholders affected and putting in place mechanisms to ensure vulnerable and marginalised groups are not disproportionately affected.
Resource Allocation

16. The Commission notes that the reform process of the adult care system may entail adjustments to how care and support will be funded. While it is for each State to determine how it allocates its funds and provides assistance, international human rights law delivers a framework within which the State must operate. With regard to economic, social and cultural rights, the UK Government and NI Executive must respect, protect and fulfil the Convention rights progressively, using their maximum available resources.4

17. The Committee on Economic, Social and Cultural Rights (CESCR) has emphasised that ‘even in times of severe resource constraints, States parties have the duty to protect the vulnerable members of society’.5 It added that ‘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’.6

18. The CESCR has recognised the negative impacts economic and financial crises can have on progressive realisation of economic, social and cultural rights. However, it has stressed that ‘States should not act in breach of their obligations under the Covenant when making adjustments in the implementation of those Covenant rights’.7

19. The Commission notes that currently the majority of adult social care in NI is provided by the private or voluntary sector. Moreover, the consultation document recognises that ‘regardless of provider, the majority of adult social care provided in NI is wholly or part-funded by government’.8 Independent of how the future balance will be divided, the State cannot absolve itself of its duty to protect. International standards require that appropriate legislative and other measures are taken and sufficient resources allocated to ensure that physical, mental and social care and support are not negatively affected by privatisation. The Commission advises that procurement decisions are informed by human rights standards and that safeguards are established to ensure private and voluntary sector care providers comply with human rights law. This is

4 Article 2(1) ICESCR.
5 CESCR, General Comment No. 6, The economic, social and cultural rights of older persons, 8 December 1995, at para 17.
6 CESCR, General Comment No. 20, Non-discrimination in economic, social and cultural rights (Art. 2 Para. 2), 2 July 2009, at para 38.
explicitly articulated in the Human Rights Act 1998, which applies to anyone carrying out ‘functions of a public nature’.9

20. The Commission advises that any future reforms of economic policies, budget allocations and other economic measures concerning the adult care and support system should be compliant with the Department’s obligations under the ICESCR.

B. The Right to Independent Living and Participation in the Community

21. The Commission notes the recurrence of the underlying values of independence and inclusiveness throughout the consultation document. The Commission welcomes the Department’s commitment to providing care and support services, which aim to facilitate individuals to live independent, healthy, active and inclusive lives.

22. The right to live independently and to participate in community life underpins and is dependent on the full enjoyment of other human rights and is closely related to the HRBA’s participatory requirements. This right is incorporated in the UNCRPD, which establishes it as a substantive right in Article 19 and includes it in Articles 9 (Accessibility), 20 (Personal Mobility), 25(c) (Provision of health services in proximity of the community) and 26 (Habilitation and Rehabilitation). Articles 3(a) and (c) UNCRPD also recognise the independence of persons and their full and effective participation and inclusion in society as two of the overarching and foundational principles of the Convention.

23. The UNCRPD establishes the rights of persons ‘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’.10

24. The Commission welcomes the Department’s recognition of the social model of disability, which forms the basis of the legal obligations enshrined in the UNCRPD. As the Commission has previously noted, the social model of disability recognises that it is the ‘society as a whole which is responsible for creating barriers to full participation of persons with disabilities, and it is the society as a whole which has the responsibility to remove them’.11 Systemic barriers, negative attitudes and exclusion (purposely or inadvertantly) by society must therefore be identified and efforts undertaken to eliminate them.

9 Section 6(3)(b) The Human Rights Act; see also Section 145 the Health and Social Care Act 2008.
10 Article 1 UNCRPD.
25. The Council of Europe Recommendation (2004)10 concerning the protection of the human rights and dignity of persons with mental disorder requires persons with mental disorders be cared for in the least restrictive environment.12 Similarly, the UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care state that ‘the treatment of every patient shall be directed towards preserving and enhancing personal autonomy’.13 Principle 3 asserts that that each ‘person with a mental illness shall have the right to live and work, as far as possible, in the community’.

26. The UN Principles on Older People equally define independence and participation as two of their five foundational principles. Alongside a number of recommendations, they encourage governments to enable older persons to remain integrated in society and to participate actively in the planning and implementation of policies, by which they are affected.

27. The Second World Assembly on Ageing in 2002, saw the adoption of a Plan of Action and a Political Declaration by representatives on behalf of their governments, also known as the Madrid International Plan of Action on Ageing. The UK government representatives thereby pledged to ‘promote independence, accessibility and the empowerment of older persons to participate fully in all aspects of society’.14

28. The Commission notes that the concept of Personalisation and Direct Payments within the care system, aims to increase the individual’s control over care received. While the Commission welcomes a participatory approach through which individuals can contribute in decision-making processes, the Commission recalls that the provision of direct payments does not release the NI Executive from its duty to protect. In particular, the Department must ensure that placing budgetary responsibilities upon vulnerable individuals does not unduly burden them and increase such vulnerabilities. It is further necessary to consider how legal certainty can be provided, so that individual recipients of direct payments are protected when contracting private services through the use of public money. Additionally, the Commission reiterates its advice from the ‘Transforming Your Care’ consultation, in which it stated that ‘it is the responsibility of the NI Executive to ensure as

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13 Principle 9(4) UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.
14 Article 14 Madrid International Plan of Action on Ageing.
far as is possible that the recipient of a direct payment makes a genuinely autonomous decision’.  

C. Availability, Accessibility, Adequacy and Quality

29. The full enjoyment of disabled and older persons’ rights to independent lives and participation in community life in the social care context is largely dependent on the full enjoyment of other substantive economic, social and cultural rights, especially the rights to health, adequate housing and social security. While laws and policies may provide for these rights, the Department must also ensure care solutions can in practice, effectively be enjoyed by those who require them. The Department must thus ensure that the availability, accessibility, adequacy and quality of physical, mental and social care are guaranteed for all on an equal basis.  

The Commission welcomes that these elements are also apparent in the founding principles identified in the consultation document, in particular the principles of equity, equality and diversity and quality.

Availability

30. The Department must take the appropriate measures to ensure that care facilities, goods and services are sufficiently available, both in urban and rural areas. Health care facilities, goods and services must thereby pay due regard to the underlying determinants of health. Equally, care facilities must meet the requirements of availability stipulated by the right to adequate housing. Social security benefits must also be available to individuals falling within the recognised social risks and contingency categories.

31. To enhance independence, the availability of habilitation and rehabilitation services are of particular importance. The CESCR has referred to the requirement of ‘preventive, curative and rehabilitative health treatment’ to enhance the functional capacities

15 Northern Ireland Human Rights Commission, Advice on ‘Transforming Your Care: A Review of Health and Social care in Northern Ireland’.
16 CESCR, General Comment No. 14, The right to the highest attainable standard of health, (Art. 12), 11 August 2000, at para 12; General Comment No. 19, The right to social security, (Art. 9), 23 November 2007.
17 Article 25(c) UNCRPD requires health services to be provided ‘as close as possible to people’s own communities, including in rural areas’; CESCR, General Comment No. 14, The right to the highest attainable standard of health, (Art. 12), 11 August 2000, at para 12(a).
18 Ibid. The underlying determinants of health include: safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs.
19 CESCR, General Comment No. 4, The right to adequate housing, (Art. 11), 13 December 1991, at para 8(b).
20 CESCR, General Comment No. 19, The right to social security, (Art. 9), 23 November 2007, at para 11.
and autonomy of older persons. Similarly, Article 26 UNCRPD places an obligation on the State to provide comprehensive habilitation and rehabilitation services for persons with disabilities. In this respect, the Commission welcomes the Department’s recognition of the importance of preventive and rehabilitative health care.

**Accessibility**

32. The element of accessibility requires that care provided be accessible to all on an equal basis, that it be physically accessible and economically affordable. It also provides that individuals have access to information and communication.

33. *Equal and non-discriminatory access* to care facilities, goods and services must be guaranteed, in order to meet core human rights obligations. Both general and specific provisions focusing on particular groups are established by the ECHR, ICCPR, ICESCR, ICERD, CEDAW and UNCRPD.  

34. Particular attention should further be afforded to the issue of multiple discrimination. This has been highlighted by the UNCRPD concerning women with disabilities, as well as by The Committee on the Elimination of Discrimination against Women (CEDAW Committee) regarding older women suffering discrimination on grounds of sex or gender and age. With regard to the right to social security, special attention should be afforded to certain individuals and groups that have traditionally faced difficulties in exercising this right.

35. *Physical accessibility* of care facilities, goods and services encompasses facilitating mobility and adapting living environments, so individuals can effectively exercise their rights and benefit from the care solutions provided. Considering the difficulties in mobility older persons and persons with disabilities can face, this element may involve providing tailored solutions for individuals with particular requirements.

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22 *Article 14 ECHR and Article 1 Protocol 12 (2000); Article 26 ICCPR; Article 2(2) ICESCR; Article 1(1) ICERD; Article 1 CEDAW; Article 5 UNCRPD.*

23 *Article 6 UNCRPD.*


25 These include, inter alia, women, the unemployed, workers inadequately protected by social security, persons working in the informal economy, sick or injured workers, people with disabilities, older persons, adult dependents, domestic workers, homeworkers, minority groups, refugees, asylum-seekers, returnees, non-nationals, prisoners and detainees. CESCR, General Comment No. 19, *The right to social security*, (Art. 9), 23 November 2007, at para 31.
36. Article 9 UNCRPD on accessibility requires that persons with disabilities are provided access to the physical environment, transportation, as well as facilities and services both in urban and rural areas. Similarly, the CESCR emphasises the importance of providing adequate means of transport, undertaking urban rebuilding and development planning, in order to facilitate mobility and ensure social integration of older people.26

37. Economic affordability includes the provision of affordable care solutions and mechanisms to ensure individuals, which lack funds or have limited capacities, are not obstructed from exercising their rights. The right to social security is particularly important in this respect.

38. Article 9 ICESCR guarantees the right to social security and social insurance for everyone. In General Comment No. 19, the CESCR defines it as a

‘right to access and maintain benefits, whether in cash or in kind, without discrimination in order to secure protection, inter alia, from (a) lack of work-related income caused by sickness, disability, maternity, employment injury, unemployment, old age, or death of a family member; (b) unaffordable access to health care; (c) insufficient family support, particularly for children and adult dependents’.27

39. The European Social Charter provides for the right to social security (Article 12 (1)), the right to social and medical assistance (Article 13) and the right to benefit from social welfare services (Article 14). These rights are inextricably linked to the European Code of Social Security and the ILO Minimum Standards. The latter two treaties articulate the minimum standards applicable and the respective Committees assess the member States’ compliance.

40. While Article 12 of the European Social Charter outlines the framework for a social security system and its minimum standards, Article 13 guarantees that anyone without adequate resources has the right to social and medical assistance. The European Committee of Social Rights has emphasised that ‘the Contracting Parties are not merely empowered to grant assistance as they think fit; they are under an obligation which they may be called on in court to honour’.28 The right is therefore not dependent on the discretion of the administrative authorities, but ‘must constitute an individual

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26 CESCR, General Comment No. 6, The economic, social and cultural rights of older persons, 8 December 1995, at para 33.
27 CESCR, General Comment No. 19, The right to social security, (Art. 9), 23 November 2007, at para 2.
right laid down in law and be supported by an effective right of appeal’.\textsuperscript{29}

41. The right to social welfare services guarantees in law and practice, that services are effective and accessible on an equal footing to all.\textsuperscript{30} This right includes quality of the services delivered as well as observation of the individual’s related rights to participation, appeal and a remedy.\textsuperscript{31}

42. The CEDAW Committee has also emphasised that the State should make allowances and adequate non-contributory pensions available and accessible to older women, particularly those living in remote or rural areas.\textsuperscript{32} The UNCRPD provides for a right to social protection of persons with disabilities, which includes access to retirement benefits and public housing.\textsuperscript{33} Persons with disabilities in situations of poverty should have access to assistance to disability-related expenses, counselling, training, financial assistance and respite care.\textsuperscript{34} Women and older persons with disabilities must also be ensured access to social protection and poverty reduction programmes.\textsuperscript{35}

43. \textit{Access to information and communication} is inextricably linked with the right to seek, receive and impart information\textsuperscript{36} and forms another essential element to ensuring individuals can effectively access the care and support available. This element requires the provision of accurate information related to individuals’ entitlements in easily understandable language, an appropriate form and in a timely manner without additional costs.\textsuperscript{37} It further includes the obligation to eliminate barriers to ensure individuals’ effective communication with others.

44. Article 9 UNCRPD requires measures be taken to identify and eliminate obstacles and barriers to accessibility and to ensure persons with disabilities have access to information, communications technologies and systems. It also includes the provision of other services, such as electronic, emergency, live assistance and intermediary services, as well as adaptation of public signage.

\textsuperscript{29} Digest of the Case Law of the European Committee of Social Rights, 2008, p 100.
\textsuperscript{30} Article 14 European Social Charter.
\textsuperscript{32} UN Committee on the Elimination of Discrimination against Women, General Comment No. 27 \textit{On older women and protection of their human rights}, 2010, at para 44.
\textsuperscript{33} Article 28(d) and (e) UNCRPD.
\textsuperscript{34} Article 28(c) UNCRPD.
\textsuperscript{35} Article 28(b) UNCRPD.
\textsuperscript{36} Article 19 ICCPR; Article 21 UNCRPD.
\textsuperscript{37} Article 21(a) UNCRPD.
45. The CESCR provides for similar requirements regarding specific rights, such as health, adequate housing and social security. The timely provision of understandable and accurate information is particularly crucial as it enables individuals to make informed decisions about their lives.

**Adequacy**

46. Care solutions must be appropriate, adequate and acceptable, taking into account the individual’s particular circumstances and cultural requirements. Where individuals cannot afford the care and support they are entitled to, it must also be ensured that social security benefits received are ‘adequate in amount and duration in order that everyone may realise his or her rights to family protection and assistance, an adequate standard of living and adequate access to health care’. 39

47. Regarding health care, the CESCR states that it ‘must be respectful of medical ethics and culturally appropriate’, thereby respecting the culture of individuals, as well as gender and life-cycle requirements. Adequate health care requires it to be ‘designed to respect confidentiality and improve the health status of those concerned’.

48. The UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care state that ‘every patient shall have the right to treatment suited to his or her cultural background’. 41

**Quality**

49. The Commission welcomes that quality and safeguarding form part of the Department’s founding principles, as quality represents an essential factor in ensuring the future care system is human rights compliant. The quality element applies equally to the facilities, goods and services provided, which include facilities that meet sanitation standards, scientifically approved equipment and drugs, as well as trained and skilled carers. 42

50. The failure to provide care solutions that meet the quality standards, will not only adversely impact an individual’s right to

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38 CESCR, General Comment No. 14, *The right to the highest attainable standard of health*, (Art. 12), 11 August 2000 at paras 12(b), 37, 44(d); General Comment No. 19, *The right to social security*, (Art. 9), 23 November 2007, at para 26.  
40 CESCR, General Comment No. 14, *The right to the highest attainable standard of health*, (Art. 12), 11 August 2000, at para 12(c).  
41 Principle 7(3) UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.  
42 Articles 20, 25(a) and (d) UNCRPD; CESCR, General Comment No. 14, *The right to the highest attainable standard of health*, (Art. 12), 11 August 2000, at para 12(d).
health but also the right not to be subjected to inhuman and degrading treatment, the right to life and the right to private and family life, as has been confirmed by the European Court of Human Rights in various instances.

51. No one should be hindered from accessing the care and support system, while the care solutions themselves should serve to enable individuals to regain or maintain their independence and life in the community. The Commission therefore advises that the Department take the above detailed elements into account in ensuring that each individual can effectively exercise the human rights they are entitled to.

52. The Commission highlights that there is no hierarchy of human rights and in providing care related facilities, goods and services the NI Executive may engage different rights. It is therefore important to take human rights in their entirety into account.

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43 Article 12 ICESR; Article 11 European Social Charter; Article 25 UNCRPD.
44 Paul and Audrey Edwards v UK (14 March 2002) 35 EHRR 198; Price v UK (10 July 2001) 34 EHRR 1285; X and Y v the Netherlands (26 March 1985) 8 EHRR 235.