Advice on ‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland’

Introduction

1. The Northern Ireland Human Rights Commission (‘the Commission’) pursuant to Section 69(3) of the Northern Ireland Act 1998, advises the NI Executive of legislative and other measures which ought to be taken to protect human rights. In accordance with this function the following statutory advice is submitted to the Minister for the Department of Health, Social Services and Public Safety for Northern Ireland on ‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland’ (‘the Review’).

A. The right to health and social care in the policy making and decision-taking process

2. The NI Executive is obligated under the international human rights treaties that have been ratified by the United Kingdom (UK). The right to health is protected in a number of these treaties, including: Article 12 of the UN International Covenant on Economic, Social and Cultural Rights (ICESCR); Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD); Article 24 of the UN Convention on the Rights of the Child (CRC); Article 5(e)(iv) of the UN International Convention on the Elimination of All Forms of Racial Discrimination (CERD); Articles 11.1(f) and 12 of the UN International Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW); and in Article 11 of the Council of Europe’s European Social Charter. The right to health is further protected in Article 25(1) of the UN Universal Declaration on Human Rights (UDHR).
3. The most comprehensive expression of the right to health is contained in Article 12 of ICESCR where a duty is placed on States to ‘recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’. The UN Committee on Economic, Social and Cultural Rights (hereafter ‘the Committee’) has emphasised the primary importance of the right to health by noting in General Comment No. 14 that it is ‘indispensable for the exercise of other human rights’,¹ and while it does not include a right to be healthy, it should be understood to mean, ‘the right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realisation of the highest attainable standard of health’.²

4. The NI Executive must further comply with the European Convention on Human Rights (ECHR), which is given domestic effect by the Human Rights Act 1998 (HRA). While there is no defined ‘right to health’ under this instrument, both the domestic courts and the European Court of Human Rights have determined that service provision within the health and social care system (HSC) frequently engages aspects of the ECHR and in particular, the right to life (Article 2), the prohibition on inhumane or degrading treatment (Article 3), the right to liberty and security of person (Article 5), the right to respect for private and family life (Article 8) and the prohibition on discrimination (Article 14).

5. The Commission therefore advises that the most efficient method of ensuring that the standards of international human rights law are not infringed as a consequence of any service reconfiguration based upon the Review proposals is for policy makers and HSC decision-takers to be mindful of the principles underpinning international human rights law throughout the entire decision-making process. In relation to the right to health there are five principles of note.

6. First, as with all human rights, there should be an awareness at all levels of the duty upon the NI Executive to respect,

¹ UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, ‘The right to the highest attainable standard of health, (Art. 12)’, 11 August 2000 at paras 1 and 3. Other rights and freedoms deemed to address integral components of the right to health include the right to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, and the freedoms of association, assembly and movement.
² Ibid at paras 8 and 9.
protect and fulfill the right to health.\textsuperscript{3} The obligation to fulfill incorporates an obligation to facilitate, an obligation to provide and an obligation to promote.\textsuperscript{4}

The obligation to \textit{fulfill (facilitate)} requires States \textit{inter alia} to take positive measures that enable and assist individuals and communities to enjoy the right to health. States parties are also obliged to \textit{fulfill (provide)} a specific right contained in the Covenant when individuals or a group are unable, for reasons beyond their control, to realize that right themselves by the means at their disposal. The obligation to \textit{fulfil (promote)} the right to health requires States to undertake actions that create, maintain and restore the health of the population.\textsuperscript{5}

7. Secondly, Article 2 of ICESCR requires that the NI Executive take steps ‘with a view to achieving progressively the full realisation’ of the right to health. The Committee has noted that the term ‘progressive realisation’ requires the State party to move as expeditiously and effectively as possible towards full realisation of the right to health and warns against deliberately retrogressive measures.\textsuperscript{6}

8. Thirdly, to ensure the progressive realisation of the right to health, Article 2(1) of ICESCR requires that the NI Executive invest a ‘maximum of available resources’. In General Comment No. 3, the Committee expressed the view that Article 2(1) incorporates ‘a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights’.\textsuperscript{7} The Committee further emphasised that ‘even in times of severe resources constraints … the vulnerable members of society can and indeed must be protected by the adoption of relatively low-cost targeted programmes’.\textsuperscript{8}

9. Fourth, Article 2(2) of ICESCR further requires States to guarantee that all rights under the Covenant will be exercised without discrimination. Discrimination is prohibited on the

\textsuperscript{4} Ibid, para 37.
\textsuperscript{5} Ibid.
\textsuperscript{6} UN Committee on Economic, Social and Cultural Rights, General Comment No. 3 'The nature of states parties obligations (Art. 2 Para. 1)', (14 December 1990), para 9.
\textsuperscript{7} Ibid, para 10.
\textsuperscript{8} Ibid, para 12.
grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status, sexual orientation or other status,\(^9\) concerning access to health care and the underlying determinants of health, as well as to means and entitlements for their procurement which have the effect of impairing the equal enjoyment of the right to health.\(^10\) The Committee has stressed that most programmes designed to eliminate health-related discrimination ‘can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information’.\(^11\) In this regard, States should adopt measures to address any widespread stigmatization of persons on the basis of their health status, such as mental illness.\(^12\)

10. Finally, the Office of the UN High Commissioner for Human Rights has developed a human rights-based approach for the realisation of individual rights as well as on generic programmes and initiatives, including programmes in the health sector.\(^13\) It is now used globally as a framework throughout the entire programming process, including the assessment and analysis, programme planning and design, implementation, and monitoring and evaluation stages. A human rights based approach draws on the human rights as found in the treaties ratified by the UK in order to highlight the need for governance to respect the principles of participation, empowerment, non-discrimination, transparency and accountability and to always devote paramount attention to the most vulnerable in society.

11. A human rights based approach need not be any more resource intensive than current procedures and will provide a robust normative framework within which Government can devise and operationalise its policies to ensure compliance with human rights obligations for the betterment of society as a whole. It has largely been concluded that, where such an

\(^9\) See UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, ‘The right to the highest attainable standard of health (Art. 12)’, 11 August 2000, para 18.
\(^10\) Ibid.
\(^11\) Ibid.
\(^12\) UN Committee on Economic, Social and Cultural Rights, General Comment No. 20 'Non-discrimination in economic, social and cultural rights (Art. 2 Para. 2)', (2 July 2009), para 33.
approach has not been followed, the process and outcomes are likely to be unsatisfactory in human rights terms:

A set of programme activities that only incidentally contributes to the realization of human rights does not necessarily constitute a human rights based approach to programming, where the aim of all activities is to contribute directly to the realization of one or several human rights.\(^\text{14}\)

B. Specific areas for consideration

12. In particular, after an initial analysis of the Review, the Commission notes the following areas for specific consideration:

- **Reallocation of revenue**
- **Structural changes**
- **Direct payments**
- **Expansion of the independent sector**
- **Data warehouse for GP records**

i. Reallocation of revenue

13. The Commission notes that the Review worked within the constraints of the current level of funding for the coming period, stating the revenue for health and social care to be £3,904 million in 2011/12 and £4,150 million in 2014/15.\(^\text{15}\) Over this period and by 2014/15, the Review suggests a 2% shift in the allocation of revenue away from hospital services and into either community, primary care or ‘personal and social’ services.\(^\text{16}\) The Review also notes that transitional funding of £25 million in the first year, £25 million in the second year, and £20 million in the third year will enable the new model of service to be implemented.\(^\text{17}\)

14. In General Comment No. 20, the Committee stated 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

\(^{14}\) Ibid.  
\(^{15}\) The Review, pp12, 124.  
\(^{16}\) Ibid, p124.  
\(^{17}\) Ibid, p8.
Covenant rights without discrimination"\textsuperscript{18} and further in General Comment No. 14, warned that ‘inappropriate health resource allocation can lead to discrimination that may not be overt’.\textsuperscript{19}

15. In this regard, the Commission notes the UK Treasury guidance for appraisal and evaluation of spending (the ‘Green Book’), which recommends that a distributional impact analysis be carried out during the appraisal of any financial policies and proposals to consider their impact on the NI Executive’s ability to fulfil its obligations under the international human rights treaties and refers specifically to ICESCR.

16. The Commission \textit{advises that a human rights impact analysis should be conducted to assess how any policy decision or resource reallocation resulting from the Review might impact on the NI Executive’s ability to fulfil their obligations under international human rights law and in particular Article 12 of ICESCR}. Further, the Commission advises that there is a need to ensure the adequacy of the bridging money to support the transition to more locally based diagnostic services and support being provided at home in order to avoid any retrogressive impact on the right to health.

ii. Structural changes

17. The Commission is encouraged by the Review’s model within which more of the services that currently require a hospital visit will be available locally.\textsuperscript{20} However, the Review proposes reducing the number of acute hospitals from the present number of ten to between five and seven within the next five years.\textsuperscript{21}

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\item \textsuperscript{18} UN Committee on Economic, Social and Cultural Rights, General Comment No. 20 'Non-discrimination in economic, social and cultural rights (Art. 2 Para. 2)', (2 July 2009), para 38.
\item \textsuperscript{19} “For example, investments should not disproportionately favour expensive curative health services which are often accessible only to a small, privileged fraction of the population,” UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, 'The right to the highest attainable standard of health (Art. 12)', 11 August 2000, para 19.
\item \textsuperscript{20} The Review, p45.
\item \textsuperscript{21} Ibid, p101.
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18. A human rights based approach to decision-making emphasises respect for the principle of participation. Similarly, the Committee stated in General Comment No. 14 that successful operation of Article 12 will respect the principle of ‘people’s participation’ during the formulation and implementation of national health strategies and plans of action.\(^{22}\)

In particular, the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under Article 12 ... Effective provision of health services can only be assured if people’s participation is secured by the States.\(^{23}\)

19. The Commission **advises that any future decision to reduce acute services should be preceded by the necessary public consultation with affected individuals and groups.** The consultation process undertaken by the Review should not be relied upon as satisfaction for this obligation.

20. The Committee states in General Comment No. 14 that Article 12 contains as an essential element the obligation that ‘health facilities, goods and services have to be accessible to everyone without discrimination’.\(^{24}\) One dimension of accessibility is the requirement that ‘health facilities, goods and services must be within safe physical reach for all sections of the population, especially marginalised or vulnerable groups’.\(^{25}\) Vulnerable groups include among others, older persons, persons with disabilities and indigent persons. The Commission advises **that acute hospitals should be within safe physical reach for vulnerable persons.**

21. In addition, the Committee stated in General Comment No. 20 that,

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\(^{22}\) UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, *The right to the highest attainable standard of health (Art. 12)*, (11 August 2000), para 54.

\(^{23}\) Ibid.

\(^{24}\) Ibid, para 12(b).

\(^{25}\) Ibid, para 12(b)(ii).
The exercise of Covenant rights should not be conditional on, or determined by, a person’s current or former place of residence; e.g. whether an individual lives or is registered in an urban or a rural area … or leads a nomadic lifestyle. Disparities between localities and regions should be eliminated in practice by ensuring, for example, that there is even distribution in the availability and quality of primary, secondary and palliative health-care facilities.26

22. The Commission agrees with the Review statement that the ‘rurality’ of Northern Ireland must be taken into consideration when developing the new model of care.27 Any decision for structural change needs to take account of and attempt to mitigate the potential for negative impacts on rural communities. In this regard, the Review's hospital to population ratio of 1:250,000-350,00028 should, in the Commission's view, account for rurality and an equitable distribution between the Belfast HSC Trust and the four other HSC Trusts. The Commission also notes that the Northern Ireland Ambulance Service will be under additional pressure as a consequence of a reduction in acute facilities.

23. The Commission advises that particular attention should be paid to the road infrastructure in rural communities when determining the final location of acute hospitals to ensure these facilities are provided without discrimination and within safe physical reach of vulnerable groups living in rural areas.

24. Finally, the Commission is concerned about certain gaps within the Review. Three issues are of immediate note in this regard. First, while the Review notes that 11% of looked-after children are in residential care, the recommendation of a further review is of limited assistance to this vulnerable group.29 Secondly, the Review makes no mention of the health needs of individuals within the criminal justice system and third, the Commission advises that given the delay in implementation, references to the 2007 Bamford Review do not adequately address future service provision for persons with mental health and learning disabilities.30

26 UN Committee on Economic, Social and Cultural Rights, General Comment No. 20 'Non-discrimination in economic, social and cultural rights (Art. 2 Para. 2)', (2 July 2009), para 34.
27 The Review, p27.
29 Ibid, p87 and proposals 48 and 49.
30 Ibid, pp89-93 generally.
iii. Direct payments

25. The Review supports an increase in the uptake of direct payments for persons with physical disabilities,\textsuperscript{31} persons with learning disabilities\textsuperscript{32} and persons with mental health issues.\textsuperscript{33} However, the Review does not explicitly support increased uptake for older persons.\textsuperscript{34} In this regard, the Commission notes that Government policy has for some time supported the uptake of direct payments. The Commission seeks clarity as to whether or not this remains the position regarding older persons given that the Review also acknowledges that there may be a variation between the benefits experienced by persons receiving direct payments, especially for older people and persons with mental health issues.\textsuperscript{35}

26. Direct payments are in keeping with the principles of autonomy and independence articulated in Articles 3 and 19 of the CRPD. Article 3 states that a general Convention principle is the ‘respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons’ while Article 19 emphasises that disabled persons are not obliged to live in any particular living arrangement. Similarly, the UN Principles for Older Persons provides that ‘older persons should have access to social and legal services to enhance their autonomy, protection and care’.\textsuperscript{36} However, the Commission notes that while direct payments promote the principles of autonomy and independence in theory, they may not always do so in practice. Given that each State has a prime responsibility and duty to protect, promote and implement all human rights and fundamental freedoms,\textsuperscript{37} it is the responsibility of the NI Executive to ensure as far as is possible that the recipient of a direct payment makes a genuinely autonomous decision

\textsuperscript{31} Ibid, p79 and proposal 32.
\textsuperscript{32} Ibid, p95 and proposal 68.
\textsuperscript{33} Ibid, p91 and proposal 61.
\textsuperscript{34} Ibid, pp 66-67.
\textsuperscript{35} Ibid, p67.
\textsuperscript{36} UN Principles for Older Persons, General Assembly Resolution 46/91, 16 December 1991 at para 12.
\textsuperscript{37} See among others, UN Committee on Economic, Social and Cultural Rights, General Comment No. 3 ‘The nature of states parties obligations (Art. 2 Para. 1)’, (14 December 1990) and the Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms, UN General Assembly Resolution 53/144 (9 December 1998), Article 2.
when buying health and social care. This requires a delicate balance to be achieved between the Executive affording liberty to the individual and assuming the duty to protect.

27. For example, while one of the benefits of direct payments is that it enables the payment of a family member for the provision of care, situations could arise where this may not be the desire of the individual but where internal pressure exists to employ the relative. For this reason, the Commission advises that the individual is made fully cognisant by way of a neutral presentation of information of his or her option to refuse the direct payment.38

28. Further, there are significantly contrasting responsibilities depending upon whether the recipient pays for the services of a home health agency or employs an individual directly.39 The Commission therefore advises that the NI Executive should take responsibility for the full education of patients and clients over how to manage and spend the direct payment, as opposed to relying upon voluntary sector organisations and ensure that the individual is aware of the potential for these responsibilities before the uptake.40

iv. Expanded role of the independent sector

29. The Commission notes the Review’s proposals to increase independent sector involvement in the provision of health and social care,41 in particular through the provision of intermediate care, such as step-up/step-down beds and short-term reablement support42 and through expanded support for persons with long-term conditions.43 Similarly, the Review anticipates that increased uptake of direct payments may mean a more diverse range of provision, including that from the voluntary sector.44 The Commission

38 The Review, p49. In a 2008 GB study by Carers UK, 5% of people are quoted as ‘feeling they were forced into having a direct payment without knowing enough’. See, Carers UK: the voice for carers ‘Choice or Chore?’ (November 2008), p 5.
39 For example, direct employment incurs the responsibilities of an employer concerning payment of taxes, work-related injuries and holiday pay.
40 The Review, p51.
41 Ibid, p7, The Review specifies as one of its key themes a ‘greater choice in service provision, particularly non-institutional services, using the independent sector’.
43 Ibid, p72 and proposal 22
understands that the ‘independent sector’ refers to voluntary and community groups, as well as the private sector.

30. Accountability is emphasised in the human rights based approach to governance and in General Comment No. 14, the Committee states that,

The national health strategy and plan of action should also be based on principles of accountability... since good governance is essential to the effective implementation of all human rights, including the realisation of the right to health... States should take appropriate steps to ensure the private business sector and civil society are aware of, and consider the importance of, the right to health in pursuing their activities.  

31. Under section 145 of the Health and Social Care Act 2008, private care homes are accountable for breaches of the ECHR as provided for in sections 1 and 6 of the HRA. The Commission further advises that other independent providers of health and social care when funded by the State are to be treated as similarly accountable for any breach of the ECHR in accordance with the intention of Parliament as expressed by Parliamentary Under-Secretary of State for Quality, Lord Howe in a recent statement delivered to the House of Lords. Lord Howe proclaimed ‘clearly and unequivocally’ that,

The Government’s view is that all providers of publicly funded health and care services should indeed consider themselves bound by the [Human Rights] Act and the duty. This is the position that we expect private and third sector providers to follow...  

32. The Commission welcomes this expansive reading of section 6 of the HRA but remains concerned about the accountability mechanisms in place for private providers of health and social care, primarily profit-driven entities, and in particular their accountability in a direct payment context. The necessity of such protection is demonstrated in the ‘Patricia Young’ incident; here a care worker employed by an independent domiciliary care provider contracted by the South Eastern

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45 UN Committee on Economic, Social and Cultural Rights, General Comment No. 14, 'The right to the highest attainable standard of health (Art. 12)’, 11 August 2000 at para 55.  
46 HL Deb 13 March 2012 at column 238 concerning proposed amendment 292A to the Health and Social care Bill 2012.
Health and Social Care Trust was filmed depriving an elderly woman of food.\(^\text{47}\)

33. **The Commission advises that when public authorities tender for services, they include as a standardised social clause within the procurement contract, recognition of the duty to comply with the HRA when exercising functions of a public nature.**\(^\text{48}\) In addition, legal certainty should be ensured to recipients of direct payments concerning the standards of care and accountability of those they contract or otherwise employ for care services is the same as directly funded providers.

**v. Data warehouse for GP records**

34. The Commission notes the Review’s proposal that a data warehouse should be introduced to store GP records. The patient information stored in the data warehouse will be used for purposes other than direct clinical care, such as planning and commissioning, research, audit and governance, benchmarking and performance improvement and will be used by staff at the Trust, HSCB and DHSSPS levels.\(^\text{49}\) The Review stipulates that ‘where necessary’ the data should be anonymised.\(^\text{50}\)

35. The right to privacy is enshrined in Article 17 of the UN International Covenant on Civil and Political Rights (ICCPR) and Article 8 of the European Convention on Human Rights (ECHR). Expanding on Article 17, the UN Human Rights Committee stated in General Comment No. 16 that ‘effective measures have to be taken by States to ensure that information concerning a person’s private life does not reach the hands of persons who are not authorised by law to receive, process and use it, and is never used for purposes incompatible with the Covenant’.\(^\text{51}\)

36. In *S and Marper v the United Kingdom*, the European Court of Human Rights held that government storage of personal data containing information regarding a person’s health fell within the remit of Article 8 and that,

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\(^48\) Human Rights Act 1998, section 6(3).

\(^49\) *The Review*, pp73, 120-121 and proposal 92.

\(^50\) Ibid, p121.

\(^51\) UN Human Rights Committee, General Comment No. 16, ‘The right to respect of privacy, family, home and correspondence, and protection of honour and reputation (Art. 17)’, 8 April 1988 at para 10.
The protection of personal data is of fundamental importance to a person's enjoyment of his or her right to respect for private and family life... The domestic law must afford appropriate safeguards to prevent any such use of personal data as may be inconsistent with the guarantees of this Article... The need for such safeguards is all the greater where the protection of personal data undergoing automatic processing is concerned... The above considerations are especially valid as regards the protection of special categories of more sensitive data (see Article 6 of the Data Protection Convention).  

37. Article 6 of the Data Protection Convention details personal data concerning health as one of the special categories in need of particular consideration. Since domestic courts are obliged to 'take into account' the jurisprudence of the ECtHR when interpreting the Convention rights, the Commission advises of the need for stringent safeguards in regard to the use of the GP records database and would suggest that a default policy of anonymisation is more likely to be considered an 'adequate guarantee' of protection from abuse than a 'where necessary' stipulation.

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52 Case of S and Marper v the United Kingdom, European Court of Human Rights, Application No. Applications nos. 30562/04 and 30566/04, 4 December 2008, at para 103. The case concerned the retention of fingerprints, cellular samples and DNA profiles of acquitted persons under section 64 of the Police and Criminal Evidence Act 1984 (Northern Ireland having equivalent provisions in the Police and Criminal Evidence Order (NI) 1989) for an indefinite period and determined that lack of clear guidelines on appropriate use was a disproportionate interference with the applicants Article 8 rights and not necessary in a democratic society.