

Irish Heart Foundation

Submission to the United Nations Universal Periodic Review

Twelfth Session of the Working Group on the UPR Human Rights Council

6th October 2011

EXECUTIVE SUMMARY

This submission focuses on the Universal Periodic Review in relation to health, disability, rehabilitation and equality.

I. BACKGROUND AND FRAMEWORK

1. Established in 1966, the Irish Heart Foundation is the national charity supporting people with heart, stroke and blood vessel disease. The Foundation promotes policy changes that reduce premature death and disability from cardiovascular disease and advocates for better patient treatment and services.

II. PROMOTION AND PROTECTION OF HUMAN RIGHTS ON THE GROUND

A. Cooperation with human rights mechanisms

1. Scope of international obligations (e.g. treaty implementation etc.)

2. Many of the obligations in the six human rights treaties to which Ireland is a party have not been incorporated into Irish law. In relation to health and disability, Ireland has not ratified the UN Convention on the Rights of People with Disabilities and its Optional Protocol. Ireland needs to develop a culture in which ratified international treaties are applied at national level.

2. Constitutional and legal reforms aimed at protecting human rights

3. Ireland's legal system is based on the Constitution, Bunreacht na hÉireann, which was drafted in 1937 prior to the development of most international human rights standards. The right to health is referred to in the Constitution only as Directive Principles for Social Policyⁱ. More recently, equality legislationⁱⁱ protects against discrimination under nine grounds, including disability, in relation to areas such as employment, goods, services and education. However, government functions and policies fall outside the scope of much of this legislation.

3. Institutional and human rights infrastructure (e.g. activities of National Human Rights Institutions, human rights education and awareness)

4. A small number of statutory organisations with responsibility for human rights and equality exist – the Irish Human Rights Commissionⁱⁱⁱ, the Equality Authority^{iv} and the National Disability Authority^v. Recent years have seen extremely deep cuts in their funding with subsequent reductions in staff levels and in the scope of their programmes of work.^{vi}

4. Policy measures (e.g. National Action Plans)

5. There is no Human Rights Action Plan. There is no Government Ministry designated to protect and promote human rights. Over time the responsibility for the promotion equality and disability have moved between the Departments of Justice, Health and Community.

Neither legislation nor Government policy is systematically proofed from a human rights perspective.

Recommendations

- Ensure the independence and the security of funding for independent human right bodies.
- A mechanism should be developed to enable UN recommendations on treaty implementation to be presented to the Oireachtas [national parliament].
- Develop a Human Rights Action Plan for a whole Government approach to the promotion of human rights and equality.

B. Implementation of International Human Rights Obligations

1. Equality and non-discrimination

Capacity legislation

6. Quality of life and autonomy in decision making for people with neurological conditions (such as stroke), some older people and people with intellectual disabilities is severely limited because of the State's failure to provide supportive mental capacity legislation. Ireland still operates under the *Lunacy Regulation (Ireland) Act 1871*^{vii}. The lack of a legal framework for advanced care directives^{viii} also limits the ability of people to make decisions about their healthcare and end-of-life care.

Recommendations

- Ratify and comply with the UN Convention on the Rights of Persons with Disabilities and the Optional Protocol to that Convention.
- Enact and implement Mental Capacity legislation and a legislative framework for advanced care directives based on the recommendations of the Law Reform Commission and the Irish Human Rights Commission.

2. Right to health

Access to healthcare

7. Ireland has a public health system, providing free healthcare to citizens. However, as a result of long waiting lists and problems in access to treatments a large proportion of citizens have private health insurance^{ix}. As such access to healthcare is based on ability to pay within a strictly two tier system.

8. In the late 1990s and early 2000s, Ireland experienced an unprecedented economic boom. During this time of high economic growth and increased tax income for the state, health and social services budgets increased. However, even during the boom, some citizens were unable to access the services they required or were subject to delays in receiving essential services because they lacked the ability to pay for private healthcare. Ireland is now enduring a banking and fiscal crisis and there have been swingeing cuts applied to healthcare budgets^x. Recent years have also seen an increase in user charges, including increases in the threshold citizens must pay before the drug payment scheme applies, the introduction of prescription charges for those in receipt of medical cards (which are intended for those who cannot afford to pay for care), and major increases in private health insurance premiums, which have

reduced many citizens' access to care. The Irish Heart Foundation also understands that the Department of Health may be considering the development of eligibility criteria for health services^{xi} which may have the effect of further limiting citizens' access to healthcare. The Irish Heart Foundation fears that the ongoing reduction in health services which may follow will have extremely negative impacts on citizens' health. The new Programme for Government^{xii} commits to the development in the coming years of a 'universal, single-tier health service, which guarantees access to medical care based on need, not income' (pg.31).

9. The human right to health has not been generally incorporated into Government policy^{xiii}. In particular, the 2001 national health policy, *Quality and Fairness – a health system for you*^{xiv} did not take a human rights approach. In 2002, the Committee on Economic, Social and Cultural Rights recommended that Ireland, 'review the recently published *National Health Strategy with a view to embracing a human rights framework in that strategy*'^{xv}.

10. Unacceptable delays in access to treatment exist in many areas of Irish healthcare. Access to treatment is impeded by high costs for patients and by staff and service shortages. One example of this is access to neurological care services. A survey of people with neurological conditions and their families and carers conducted in 2011^{xvi} illustrates the delay in access to these particular services.

11. The historical development of health and social care services in Ireland, many of which developed from charitable, religious organisations, has led to a situation where many health services are provided by voluntary organisations contracted by the state. In spite of the reliance of the state healthcare system on voluntary and charitable providers to deliver essential health and care services to those who need them, the state fails to recognise voluntary organisations as partners in the provision of healthcare. These organisations, which have direct experience of providing for the needs of patients, are often not properly consulted on the direction of policy or in the process of implementation. Voluntary providers of services have experienced severe cuts to their state funding in recent years and this is having a detrimental effect on the services provided to the users of these services.^{xvii}

12. Through the development of the Health Service Executive's Clinical Care Programmes^{xviii} a new approach to developing pathways of care for diseases and to achieving improved patient outcomes is being displayed. This illustrates that the current economic crisis does not need to impinge on the state's ability to progressively improve healthcare and health indicators.

Accountability for healthcare

13. Accountability for ensuring progressive developments in the right to health in Ireland must be secured. Since 2005, there have been considerable changes in the structure of health service provision in Ireland, from regionally controlled health boards to a centralised health executive and further significant change is promised by the newly elected government.^{xix} Poor communication and management of this process of change, combined with healthcare scandals^{xx} have led to a sharp decline in patients' trust of the system. The newly-elected Government (March 2011) has committed to a further overhaul of the health system.^{xxi}

14. Changes in the health service have resulted in the separation of the policy and implementation functions of the Department of Health, with responsibility for implementation transferring to the Health Service Executive. This has insulated the Department of Health from accountability for the provision of quality services and equitable

access to these services^{xxii}. It has also led to a disjuncture between health policy planning and the delivery of services.

15. A person's health will determine their ability to participate in and contribute to society and the Irish state has not displayed the understanding that a strong health system is an essential part of an equitable society. The current health system is fractured and care between the different health sectors is not well integrated. The lack of defined care pathways for many conditions means that patients often have to negotiate their care on their own at the complex junctures between primary, acute and community care services.

Access to rehabilitation^{xxiii}

16. Access to rehabilitation services is severely limited in Ireland (in part because the country currently only has 7 Consultants of Rehabilitation Medicine working in the public system^{xxiv}), reducing many people's quality of life following a stroke, trauma, etc. Rehabilitation services are centralised in the single National Rehabilitation Hospital which requires individuals seeking treatment to waiting for long periods, to travel long distances from across the country for rehabilitation and to be separated from their family and communities during their treatment. Stroke is one area which illustrates the real lack of access to rehabilitation services and the impact which this has on people's quality of life.^{xxv}

17. There have been significant and ongoing delays by the Government in developing and publishing a rehabilitation policy/ strategy. The Department of Health embarked on the development of a national policy/strategy for the provision of rehabilitation services, establishing a Working Group in July 2008.^{xxvi} The report of the Working Group was due in the first quarter of 2010 – it remains unpublished in March 2011. In the interim the Health Service Executive has developed a Clinical Programme for Rehabilitation Services. The availability of funding for the implementation of this programme is as yet unclear.

Supports for older people

18. Equitable and timely access to healthcare should be a right for all, regardless of age. It is essential that the Irish healthcare system evolves to become more patient-focused and eliminates all existing age discrimination. As currently constituted, the provision and funding of healthcare in Ireland separates patients by age, rather than medical need.^{xxvii} A patient-centred health service would ensure that access to services is needs-based, with no reference to age cut-off.

19. There is no healthcare strategy for older people.^{xxviii} Healthcare for older people has been neglected and little consideration has been given to their special needs, partly because of the legacy attitude towards ageing and partly because the numbers of people reaching old age were relatively few until recently. This indifference is borne out by the relative failure of the health service to provide adequately for the prevention, prompt treatment and early rehabilitation of the conditions that contribute most to invalidism and institutionalisation among elderly people in Ireland, including cerebrovascular disease resulting in stroke and dementia; angina, heart attack and heart failure; and peripheral vascular disease. Too often the victims of these conditions are consigned to institutions for expensive continuing care when the provision of proper facilities in the community would allow many to function independently in a non-institutional environment.

20. Supports for older people and people with disabilities to live in their own homes are under-developed and / or subject to considerable delays.^{xxix}

Supports for carers

21. There are 161,000 family carers in Ireland^{xxx}. They play a crucial role in the care of citizens and their contribution should be recognised. Following wide consultation with carers, the state delayed the development of a National Carers Strategy for many years and it still remains unpublished^{xxxi}.

Vulnerable groups

22. The right to health is particularly important for the poorest and the most vulnerable. In Ireland, the State has been remiss in its obligation to provide access to healthcare for the entire population, particularly for the poorest and the most vulnerable^{xxxii}. Health status remains highly differentiated among different groups in Irish society.^{xxxiii} Recognition of vulnerable groups (including older people, those with chronic illnesses and children) in Irish health policy and addressing how they may be particularly affected by health policies has been poor. There are limited opportunities for the recipients of healthcare to be involved in policy development and implementation, although the very recent establishment of patient forums by the Health Service Executive provide the opportunity to develop patient and patient representative organisation engagement within the health system.

Health information

23. There is particularly limited collection of health data in Ireland, making it very difficult to monitor the progressive realisation of the right to health and to develop evidence-based policy. Bar the National Cancer Registry – which only began nationwide registration in 1994 – there are no formalised nationwide registries of other diseases, including for cardiovascular disease, Ireland's biggest killer. In 2008, the Department of Health and Children began consultations on a Health Information Bill which would establish a legislative framework to collect information to enhance medical care and patient safety. The Bill remains unpublished.

Recommendations

- Restructure the health service to ensure equitable access for all citizens.
- Adopt a human rights approach to development of health policies. Develop a new national health strategy. Build awareness among health professionals and those working in health policy development of the right to the highest attainable standard of health.
- Re-instate responsibility for health policy making, planning and delivery in the Minister for Health and the Department of Health.
- Develop strong mechanisms for accountability of health providers and policy makers to the Houses of the Oireachtas.
- Eradicate age discrimination in healthcare provision and ensure that services are provided on the basis of individual need.
- Publish and implement the Rehabilitation Strategy and the Carers' Strategy.
- Develop a robust legislative framework for health information collection, including the enactment of a Health Information Act. Develop disease registers and data collection at each level of health care provision.

APPENDIX

ⁱ Bunreacht na hÉireann (Constitution of Ireland) – Article 45 – Directive Principles of Social Policy
 4. 1° *The State pledges itself to safeguard with especial care the economic interests of the weaker sections of the community, and, where necessary, to contribute to the support of the infirm, the widow, the orphan, and the aged.*

2° *The State shall endeavour to ensure that the strength and health of workers, men and women, and the tender age of children shall not be abused and that citizens shall not be forced by economic necessity to enter avocations unsuited to their sex, age or strength.*

...
ⁱⁱ Equal Status Acts 2000-2008 and the Employment Equality Acts 1998-2008.

ⁱⁱⁱ Irish Human Rights Commission, www.ihrc.ie.

^{iv} Equality Authority, www.equality.ie

^v National Disability Authority, www.nda.ie

^{vi} For example, in 2008 the budget of the Equality Authority was cut by 43%. See *Irish Independent*, 'Equality Authority chief quits after €2.5m Budget cut', available at: <http://www.independent.ie/national-news/equality-authority-chief-quits-after-836425m-budget-cut-1572746.html>.

^{vii} The Law Reform Commission made recommendations for changes to the capacity legislation, these have yet to be implemented. See Law Reform Commission (2006). *Vulnerable Adults and the Law*. LRC: Dublin. Available at: <http://www.lawreform.ie/fileupload/Reports/Report%20Vulnerable%20Adults.pdf>.

^{viii} In 2009, the Law Reform Commission made recommendations on advanced care directives to the Government. See Law Reform Commission (2009). *Bioethics: Advanced Care Directives*. Law Reform Commission: Dublin. Available at: <http://www.lawreform.ie/fileupload/Reports/Report%20Bioethics.pdf>.

^{ix} Statistics published by the Health Insurance Authority show that the size of the health insurance market peaked with 2.3 million customers at the end of 2008 and declined to 2.25million by the end of March 2010 (a decline of 2.3% in 15 months). See Health Insurance Authority Press Release 8th June 2010,

'Health Insurance Authority publishes national survey of the private health insurance market in Ireland'.

Available at: <http://www.hia.ie/publication/press-releases.htm>

^x Under the Government's *National Recovery Plan 2011-2014*

(<http://www.budget.gov.ie/The%20National%20Recovery%20Plan%202011-2014.pdf>), the health budget will be cut by €1.4bn. See *The Irish Times*, 24th November 2010, 'Health Budget to be cut by €1.4bn'. Available at <http://www.irishtimes.com/newspaper/breaking/2010/1124/breaking44.html>.

^{xi} Referenced in the opening address made by the then Minister for Health and Children at the *Resource Allocation, Financing and Sustainability in Healthcare Conference* at the Economic and Social Research Institute (ESRI) on 19th October 2010.

^{xii} Government of Ireland (March 2011). *Programme for Government*. Available at:

http://www.taoiseach.gov.ie/eng/Publications/Publications_2011/Programme_for_Government_2011.pdf.

^{xiii} Ireland ratified the International Covenant on Economic, Social and Cultural Rights in 1989. Article 12 of that Covenant provides for the right of everyone to the highest attainable standard of physical and mental health.

^{xiv} Department of Health and Children (2001). *Quality and Fairness – a health system for you*. Government of Ireland: Dublin. Available at: <http://www.dohc.ie/publications/pdf/strategy.pdf?direct=1>.

^{xv} UN Economic and Social Council, *Concluding Observations of the Committee on Economic, Social and Cultural Rights : Ireland*. 05/06/2002.

E/C.12/1/Add.77. (Concluding Observations/Comments)

^{xvi} Amongst other findings: 38% of people with neurological conditions reported waiting longer than six months to be diagnosed with their condition. 42% had waited over six months for a service for their neurological condition. See Neurological Alliance of Ireland (2011). *Experiences of Neurological Care in Ireland: Report on Nationwide Research Survey carried out by the Neurological Alliance of Ireland 2011*. Available at: <http://www.msreadathon.ie/uploads/File/NAI%20full%20survey%20report.pdf>

^{xvii} For example see *The Irish Times*, 8th July 2010, 'We have rights. All we ask is that you uphold them'. Available at: <http://www.irishtimes.com/newspaper/ireland/2010/0708/1224274268285.html>

^{xviii} The HSE's Quality and Clinical Care Directorate is developing a wide range of National Clinical programmes. The programmes cover a range of clinical areas with a view to reducing the lengthy out patients'

waiting lists around the country and improving standards of care in all key health specialties. See <http://www.hse.ie/eng/about/Who/clinical/natclinprogrammes/>

^{xix} See description of health service reforms contained in a recent report drafted for the Department of Health and Children, Department of Health and Children (2010). *Resource Allocation, Financing and Sustainability in Health Care, Evidence for the Expert Group on Resource Allocation and Financing in the Health Sector, Volume 1*. Economic and Social Research Institute: Dublin.

‘The Irish health-care system underwent substantial organisational reform in 2005, partly in response to the recommendations of a number of key reports on the Irish health-care system in the early 2000s, most notably the Brennan and Prospectus reports (Brennan, 2003; Prospectus, 2003). The central aim of the Health Service Reform Programme was to improve the availability and quality of health-care services by improving the planning, management, delivery and evaluation of services and their respective accountability arrangements (Health Service Reform Programme, 2006). The key bodies in the reformed system included a re-structured Department of Health and Children (DoHC), a newly established Health Service Executive (HSE) and a new regulatory agency, the Health Information and Quality Authority (HIQA).

The DoHC performs a stewardship function for the sector and provides support to the Minister for Health and Children, who is politically accountable for the health service. The DoHC is responsible for strategic policy and planning, evaluation of resource allocations and development of an effective legislative and regulatory framework for the system. The HIQA was fully established in 2007 and is responsible for promoting quality and safety in Irish health and social care services.

The HSE manages the operation of the health service, replacing 10 regionally-based Health Boards. Following recent restructuring in October 2009, the Integrated Services Directorate (ISD) now incorporates the previously separate offices of the National Director for Primary, Community and Continuing Care (PCCC) and the National Director for Hospitals (NHO)...’ (pg.13).

^{xx} For example see, RTE News, 16th October 2007, ‘Health system let down Susie Long – Ahern’ <http://www.rte.ie/news/2007/1016/health.html>

^{xxi} Government of Ireland (March 2011). *Programme for Government*. Available at:

http://www.taoiseach.gov.ie/eng/Publications/Publications_2011/Programme_for_Government_2011.pdf.

^{xxii} Large volumes of Parliamentary Questions directed to the Department of Health have tended to be forwarded for direct reply by the Health Service Executive. This means the responses are not recorded in the parliamentary records, although they are available to search on the HSE website. For example, in 2008 the Minister forwarded 58 per cent of parliamentary questions directed to her Department to the HSE. See *Irish Medical Times*, 25th February 2009, ‘Over half of Department PQs forwarded to HSE’. Available at: <http://www.imt.ie/news/health-management/2009/02/over-half-of-department-pqs-forwarded-to-hse.html>

The Oireachtas Committee on Health has continued to be progressive in addressing healthcare debates and allows the airing of different perspectives and experiences of healthcare. As a forum for debate it has been effective, but its limited powers have not enabled it to have any significant impact on the government policy or the actions of health authorities. See Joint Oireachtas Committee on Health and Children press release, 27th January 2011, ‘Exposing Weaknesses in System and Influencing Policy among Successes of Health Committee’. Available at: <http://www.oireachtas.ie/parliament/mediazone/pressreleases/name-2082-en.html>

^{xxiii} The right to habilitation and rehabilitation is protected under the International Convention on the Rights of Persons with Disabilities, which Ireland has signed but not yet ratified.

^{xxiv} There are seven Consultants of Rehabilitation Medicine working in Ireland. The National Rehabilitation Hospital (NRH) has only 109 beds. Ireland should have a minimum of 372 rehabilitation beds. In February 2011, 135 patients were on a waiting list for a bed in the NRH. See *Irish Examiner*, 3rd February 2011, ‘Number of rehab consultants well below minimum’. Available at <http://www.irishexaminer.com/ireland/kfeyeyauojql/rss2/>

^{xxv} In September 2010, the Irish Heart Foundation published the *The Cost of Stroke in Ireland – estimating the annual economic cost of stroke and transient ischaemic attack in Ireland* (available at <http://www.stroke.ie/media/pub/strokeie/cosireport.pdf>). Prepared by the ESRI and the Royal College of Surgeons in Ireland the report provides the most comprehensive research ever carried out in Ireland on the economic burden of stroke and the potential cost benefits of service developments.

One in five people in Ireland will have a stroke at some time in their life and it is the largest cause of acquired disability. Yet despite the massive human impact of the disease, stroke services here have never been properly funded. As a result, high levels of avoidable death and disability from stroke still exist despite strong evidence that acute service improvements would save hundreds of lives each year, whilst also saving the taxpayer millions of euro. The total cost of stroke in Ireland is up to €1 billion with direct costs accounting for up to 4% of total health expenditure. 40% of these costs are taken up by the bill for nursing home accommodation and less than €7 million a year is being spent on community rehabilitation for the up to 50,000 stroke survivors.

These stark figures highlight the need to improve the long-term functional outcomes of stroke patients and to enable them to be able to live at home rather than in a nursing home.

^{xxvi} Department of Health and Children, Working Group for the Development of a National Policy / Strategy for the Provision of Rehabilitation Services, http://www.dohc.ie/working_groups/Current/prs/

^{xxvii} Within stroke services, for example, this has resulted in serious inequities. For example, in some locations over-65s do not receive rehab services, whilst in others under-65s are ineligible for community services.

^{xxviii} The Department of Health and Children has held consultations on the development of a National Positive Ageing Strategy. See http://www.dohc.ie/issues/national_positive_ageing/.

^{xxix} Early supported discharge for suitable patients, the provision of assistance to family carers, homecare packages and adaptations to the patient's home are all vital to ensuring that patients, and in particularly older patients who may have chronic illnesses, achieve the highest possible quality of life. In many areas, there are very long waiting lists for grants which support older people and people with disabilities to live in their own home, including the Housing Aid for Older Persons Scheme and the Housing Adaptation Grant for People with Disabilities. For example see *Roscommon Herald*, 27th May 2009, 'Council has 445 people waiting for housing grants', available at <http://www.roscommonherald.ie/news/sncwmhsn/> and *The Irish Times*, 22nd June 2009, 'Funding crisis to hit housing grants for elderly says charity', cited at <http://www.cardi.ie/news/fundingcrisistohousinggrantsforelderlysayscharity>

^{xxx} Central Statistics Office (2007) *Census of Ireland 2006 Volume 11 Disability, Carers and Voluntary Activities*. Available at http://www.cso.ie/census/census2006results/volume_11/Volume11_2006.pdf.

^{xxxi} In March 2009, the then Minister for Social Protection met with the Carers' Association and announced that the National Carers' Strategy, which had been subject to wide consultation since 2007, would not be published. See Irish Health, 4th March 2009, 'Carers' Strategy scrapped by Govt'. Available at: <http://www.irishhealth.com/article.html?id=15165>.

^{xxxii} Persons in the most deprived areas in Ireland have the lowest life expectancy. The life expectancy at birth of males living in the most deprived areas in the State was 73.7 years in 2006/2007 compared with 78 years for those living in the most affluent areas. See Central Statistics Office (Dec. 2010). *Mortality Differentials in Ireland*. http://www.cso.ie/census/documents/Mortality_Differentials_in_Ireland.pdf

^{xxxiii} For example, smoking is particularly prevalent among women in lower social classes. More than half of all women aged 18-29 from the lower social groups (56%) were smokers, which was twice the rate among women in higher social groups. See Department of Health and Children (2008). SLÁN 2007. Survey of Lifestyle, Attitudes and Nutrition in Ireland. www.slán07.ie