**Questionnaire on bioethics and disability**

**Ireland’s response**

**September 2019**

This document details Ireland’s response to questions 1, 2(a), 2(b) and 6 of the questionnaire on bioethics and disability.

1. **Please provide information on the legislative and policy framework in place in your country in relation to:**
   1. **Prenatal diagnosis**

Prenatal diagnosis is available in Ireland but the provision of this service is not regulated by any specific piece of legislation.

* 1. **Disability-related abortion**

The Health (Regulation of Termination of Pregnancy) Act 2018 sets out the law governing access to termination of pregnancy in Ireland.

The Act permits termination to be carried out:

* without restriction up to 12 weeks of pregnancy;
* in cases where there is a risk to the life, or of serious harm to the health, of the pregnant woman, including in an emergency situation; and
* where there is a condition present which is likely to lead to the death of the foetus either before or within 28 days of birth.

In regard to the latter, section 11 of the Act states:

***Condition likely to lead to death of foetus***

***11.*** *(1) A termination of pregnancy may be carried out in accordance with this section where 2 medical practitioners, having examined the pregnant woman, are of the reasonable opinion formed in good faith that there is present a condition affecting the foetus that is likely to lead to the death of the foetus either before, or within 28 days of, birth.*

*(2) Of the 2 medical practitioners referred to in subsection (1)—*

1. *one shall be an obstetrician, and*
2. *the other shall be a medical practitioner of a relevant specialty.*

*(3) A termination of pregnancy shall not be carried out under this section unless each of the medical practitioners referred to in subsection (1) has certified his or her opinion as to the matters referred to in that subsection.*

*(4) The termination of pregnancy to which the certification referred to in subsection (3) relates shall be carried out—*

1. *by the obstetrician referred to in subsection (2)(a), or*
2. *where the medical practitioner referred to in subsection (2)(b) is also an obstetrician, by that obstetrician or the obstetrician referred to in subsection (2)(a).*

The Act does not provide for terminations of pregnancy to be carried out on grounds of disability.

* 1. **Informed consent to medical treatment and scientific research**

All consent to be considered valid and lawful has to be informed. Policy and legislative measures, whether wholly domestic or in furtherance of EU initiatives, require informed consent as the basis for participation in all human health research, including where the health research is based on the processing of personal data or where participation in clinical trials is involved. The Health Research Regulations 2018 (made under the Data Protection Act 2018) make explicit (informed) consent the default basis for the processing of personal data for health research purposes but also include a statutory process for a consent exemption in limited circumstances, i.e. where the research is of substantial public importance and it is impracticable to obtain consent.

The Health Service Executive has prepared and published a National Consent Policy –currently being updated- addressing consent issues across the spectrum of health interventions, receipt or use of a health service and participation in health research. It sets out general principles and then elaborates how those principles are to be applied in particular circumstances and in relation to particular groups of persons. For example, in relation to children with a disability it states that “children with disabilities have the right to express their views freely on all matters affecting them, on an equal basis with other children, with their views being given due weight according to their age and maturity. In order to realize this right, children with disabilities must be provided with disability and age-appropriate guidance material”.

The National Disability Authority has published guidance on Ethical Guidance for Research with People with Disabilities. The guidance has been drawn up through consideration of best practice internationally alongside a wide process of consultation, in particular consultation with people with disabilities. The guidance is designed to be used by those involved in funding, conducting, or managing disability research, most especially that which involves people with disabilities as participants.

In terms of ethical approval for health research, Ireland has a fragmented institution based system of research ethics committees (RECs). Historically, RECs have been established as a local institutional initiative (for example, in a hospital or university) rather than on foot of any national policy. As a result, there are several different kinds of RECs with different jurisdictions and scopes of operation.

Legislative proposals to reform the present REC structure through the creation of a National REC system supported by a National Office for Research Ethics Committees has been approved by Government and will be formally y drafted. Clinical trials of medicinal products will be one area where a National REC will be established and the Minister will be empowered to prescribe other areas.

Many disability services in Ireland are provided on behalf of the Health Service Executive by voluntary and other bodies under sections 38 and 39 of the Health Act 2004. These bodies have their own RECs. The new National REC model will provide the opportunity to change this.

Institutional RECs will not disappear under the new model. To support them in their work, the National Office for Research Ethics Committees will provide them with educational outreach and training for the promotion, maintenance and development of health research ethics in the State

1. **Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) in relation to:**
2. **The availability, accessibility and use of prenatal diagnosis**

In relation to prenatal diagnosis, the National Maternity Strategy 2016-2026 – Creating a Better Future Together, is very clear that all women must have equal access to standardised ultrasound services.

The issue of anomaly scanning is a matter of priority for the National Women & Infants Health Programme (NWIHP) within the Health Service Executive. The Implementation Plan for the Strategy, which NWIHP leads on, includes a number of actions to facilitate the provision by all maternity hospitals/units of dating and anomaly scans to all pregnant women.

Targeted allocation of development funding has enabled the number of maternity hospitals/units offering 100% access to routine anomaly scanning (i.e. at approximately 20 weeks) to increase from 7 in 2016 to 14 in 2019. In addition, University Maternity Hospital Limerick offers an anomaly scan at 32 weeks.

It is envisaged that all 19 maternity hospitals/units in Ireland will offer 100% access to anomaly scanning by the end of 2019.

1. **The availability, accessibility and use of disability-related abortion**

As set out previously, the Health (Regulation of Termination of Pregnancy) Act 2018 does not permit termination of pregnancy to be carried out on grounds of disability in Ireland.

Section 11, however, permits termination of pregnancy in cases where there is a condition present which is likely to lead to the death of the foetus either before or within 28 days of birth.

The Act was commenced in January 2019 and services for termination of pregnancy were initiated at the same time.

Under Section 20(3) of the Health (Regulation of Termination of Pregnancy) Act 2018, the Minister for Health is required to prepare a report on notifications of terminations of pregnancy received during the immediately preceding year.  The first such report will be prepared before end-June 2020; no other data will be available or published before that date.

1. **Please refer to any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of persons with disabilities in bioethical discussions.**

In addition to specific measures targeting persons with disabilities, all public bodies in Ireland have responsibility under the Public Sector Equality and Human Rights Duty established by Section 42 of the Irish Human Rights and Equality Act 2014 to promote equality, prevent discrimination and the human rights of opportunity of their employees, customers, service users and everyone affected by their policies and plans.