**Response of the Government of Ireland to the questionnaire on the rights of persons with disabilities to the highest attainable standard of health**

**Question 1: Please provide information on existing or planned legislation and policies to ensure the realization of the right to health of persons with disabilities, including current challenges and good practices.**

*Specialist Health and Personal Social Services for People with a Disability*

1. Legislative and Policy Framework

The Health Acts underpin the provision of specialist health and personal services. The majority of services are provided by voluntary, non statutory, charity organisations by arrangement with the Health Service Executive.

The Government, together with the statutory and non-statutory agencies who provide services to people with disabilities, have been working towards the goal of enabling our disabled citizens to live as independently as possible with appropriate social, housing, employment and all other mainstream supports from the State. Our aim is to transform services to a model of personally chosen supports, designed to enable the individual to live a normal life in society.

These improvements are being driven through Transforming Lives, which is the programme to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland. This transformation of our disability services means that person-centred and individually chosen community-based supports are increasingly becoming the norm, as we move from the group-based, often segregated approach of the past. People with disabilities are progressively being supported to make the type of choices about their lives which are available to everyone else in society. Work is also underway to ensure that this new approach will be underpinned by a more effective method of assessing need, allocating resources and monitoring resource use.

Please find link to the Value for Money and Policy Review of Disability Services in Ireland

<http://health.gov.ie/wp-content/uploads/2014/03/VFM_Disability_Services_Programme_2012.pdf>

1. Transforming Lives

Transforming Lives is the programme to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland.

Under Transforming Lives, disability services are migrating from an approach which is predominantly organised around group-based service delivery towards a model of person-centred, individually chosen, supports underpinned by a more effective method of assessing need, allocating resources and monitoring resource use. Under the overarching Transforming Lives framework, a complex range of inter-related projects are underway to implement different elements of the new person-centred supports model, including the moving from Congregated Settings Report, the New Directions report on adult day services and the National Programme on Progressing Disability Services for Children and Young People (0 to 18 years).

*Planned Legislation*

Ireland recently ratified the UN Convention on the Rights of Persons with Disabilities. The Convention will come into force for Ireland on 19 April 2018.

We note the provisions of article 25 and the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability and look forward to our engagement with the Committee on this and all other articles of the Convention.

Ireland launched the National Disability Inclusion strategy in July 2017 to improve the lives of people with disabilities in a practical sense, and also to create the best possible opportunities for people with disabilities to fulfil their potential. It focuses on eight key themes including health and wellbeing, equality and choice, the provision of services, accommodation, employment, transport and education. The section on health and wellbeing takes an all of government approach to ensuring that people with disabilities are supported to achieve and maintain the best possible physical, mental and emotional wellbeing.

**Question 2: Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the exercise of the right to health of persons with disabilities in general, as well as with particular focus in the following areas:**

* **Availability of barrier-free general healthcare services and programmes, which take into account all accessibility aspects for persons with disabilities;**
* **Access to free or affordable general healthcare services and programmes, including mental health services, services related to HIV/AIDS and universal health coverage;**
* **Access to free or affordable disability-specific healthcare services and programmes; and**
* **Access to free or affordable health-related habilitation and rehabilitation goods and services, including early identification and intervention.**

*Funding and Specialist Services*

In 2018, funding of €1.76 billion is being provided for health and personal social services for wide and complex range of services and supports for people with disabilities.

The services provided include:

* Residential services to around 8,500 people with disabilities at more than 1,200 locations. These facilities range from large congregated settings to community group homes to supported independent living.
* Day services for around 25,000 people at 850 different locations.
* New services and supports for 1,500 young people finishing school and rehabilitative training programmes.
* Respite residential support, amounting to 180,500 overnight stays.
* 3 million hours of personal assistance and home support.

A variety of other services are also provided under the disability services programme, including non-centre-based respite, early childhood and family support, community based medical, nursing and therapy services, rehabilitative training, and aids and appliances.

The **Health Research Board** (HRB) manages a number of databases for the Department of Health, the National Physical and Sensory Disability Database, and the National Intellectual Disability Database.

The National Ability Supports System (NASS), is to be rolled out shortly, and will replace the two systems above.

Further information, including a wide range of reports and statistics is available at

<http://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/>

**IDS-TILDA** is a longitudinal study researching ageing in Ireland among people with an intellectual disability aged 40 and over. This study, funded by the Department of Health through the Health Research Board is the first of its kind in Europe, and the only study able to directly compare the ageing of people with intellectual disability with the general ageing population.

The underpinning values of IDS-TILDA are inclusion, choice, empowerment, person centred, the promotion of people with intellectual disability, the promotion of best practice and to make a contribution to the lives of people with intellectual disability.

Further information, including a wide range of reports and statistics is available at <http://www.idstilda.tcd.ie/>

*General - Medical Card System & People with Disabilities*

The Irish Public Health System provides for two categories of eligibility for persons ordinarily resident in Ireland, i.e. full eligibility (Medical Card holders) and limited eligibility (all others). Full eligibility is determined mainly by reference to income limits. Determination of an individual’s eligibility status is the responsibility of the Health Service Executive (HSE).

Persons with full eligibility are entitled to a range of services at no cost including general practitioner services, prescribed drugs and medicines (with the exception of a €2 charge per prescribed items up to a maximum of €20 per month per individual/family), all in-patient public hospital services in public wards including consultants services, all out-patient public hospital services including consultants services, dental, ophthalmic and aural services and appliances and a maternity and infant care service. Other services such as allied health professional services may also be available to medical card holders.

The Medical Card system is administered by the HSE. Medical Card eligibility, as stated above, is generally based on an assessment of a person’s means. The relevant income thresholds can be found at the following link: <https://www.hse.ie/eng/cards-schemes/medical-card/how-to-apply/medical-cards-national-assessment-guidelines.pdf>

The HSE has discretion when deciding to grant a Medical Card to a person whose income is in excess of the relevant guidelines. The HSE makes every effort to take account of all relevant factors relating to an application for a Medical Card. In this regard a number of issues may be taken into account in making a decision: e.g. illness or medical circumstances which results in financial hardship, the cost of providing general medical and surgical services, the cost associated with the provision of medical, nursing and dental treatment, the cost of physiotherapy and speech and language therapy, transport cost to hospitals and clinics and the cost of medical aids and appliances.

It is important to note that people whose only income is from social welfare payment are automatically eligible for a Medical Card and that people who have been in receipt of certain benefits or allowances (including Illness Benefit, Invalidity Pension, Disability Allowance, and Blind Pension) for a continuous period of 12 months or more are entitled to retain their Medical Card (without a means test) for three years on taking up full-time employment from the date on which the employment commenced.

As we are aware people with disabilities are more likely to be on low incomes, either from employment or social welfare payments and therefore more likely to be eligible for and in receipt of a Medical Card on income grounds. According to the “Making Work Pay for People with Disabilities, Report to Government 2017”, there were over a quarter of a million people with disabilities receiving a social welfare illness or disability weekly payment in Ireland and almost half of these were receiving Disability Allowance. Also while some 15% of those on Disability Allowance in 2016 had experienced a spell of employment between 2010 and 2015, and 9% had been employed while in receipt of a Disability Allowance payment, their average annual earnings, for those who were in employment, during that period was approximately €10,000 and of those who were also in receipt of Disability Allowance, the average earnings was about €6,400 or approximately €120 a week.

Furthermore, according to the latest data available from the Irish Census 2011, people with disabilities are only half as likely to be in work as their non-disabled peers and the rate of employment among persons with a disability remains low (33%) relative to the working age (aged 20 to 64) population (66%) as a whole.

Persons that might be above the medical card thresholds may be eligible on income grounds for a GP Visit Card. This provides individuals with free GP Care. The associated income thresholds that apply are also outlined at the link above.

*Medical Cards for Children that qualify for the Domiciliary Care Allowance*

The Domiciliary Care Allowance (DCA) is a non-means tested monthly payment made by the Department of Employment and Social Protection in respect of a child under 16 years who requires ongoing care and attention substantially over and above the care and attention usually required by a child of the same age. The Health (Amendment) Act 2017 allowed for the provision of automatic eligibility for a medical card for children in receipt of DCA.

The DCA Medical Cards have been awarded since June 1 2017. Providing automatic eligibility for a Medical Card for children in receipt of the DCA alleviates the stress and anxiety of parents in terms of medical costs associated with their child’s disability. Parents will now not be required to undergo the process of providing family financial information, expert or medical reports and additional supporting information when applying for a Medical Card. Children who are not in receipt of DCA continue to be assessed for a Medical Card using the standard Medical Card assessment procedures.

*Medical Cards and Prescription Charges*

Medical card eligibility is based on income criteria. Discretionary cards may be available, however, in relation to large, on-going healthcare costs.

Medical card holders pay a prescription charge of €2 per item, with a maximum monthly cost of €20.

As well as giving entitlement to free healthcare and specialist therapies, a medical card also confers eligibility to essential disability aids/assistive technology (such as wheelchairs or hearing aids) free of charge, where they are prescribed. Many of these are expensive items for anyone who would otherwise have to buy them at intervals from their own pocket.

The Programme for a Partnership Government contains a commitment to reduce the cost of medicines for Irish citizens, and further reductions in the prescription charge and Drug Payment Scheme co-payment may be considered in the future, having regard to resources available.

*Health Related Schemes that may apply to people with disabilities*

**Long Term Illness Scheme:** This scheme allows people suffering from prescribed conditions or disabilities to receive drugs, medicines and medical and surgical appliances for the treatment of that condition, free of charge.

The conditions covered by the LTI Scheme are: acute leukaemia; mental handicap; cerebral palsy; mental illness (in a person under 16); cystic fibrosis; multiple sclerosis; diabetes insipidus; muscular dystrophies; diabetes mellitus; parkinsonism; epilepsy; phenylketonuria; haemophilia; spina bifida; hydrocephalus; and conditions arising from the use of Thalidomide.

**Drug Payment Scheme:** Under the Drug Payment Scheme, an individual or family in Ireland only has to pay a set maximum amount (currently €134) each month for approved prescribed drugs, medicines and certain appliances for use by that person or his/her family in that month.

*Mental Health*

Any person, regardless of nationality, who is accepted by the Health Service Executive as being ordinarily resident in Ireland has eligibility to access mental health services. The dependent children of such persons also have eligibility. Persons who have been involuntarily detained are not charged for the time that they are being treated on a psychiatric ward. Other residential care is charged at the normal rate for users that are not medical card holders. There is a maximum charge of €800 in a given year for prolonged or multiple stays at HSE run facilities. There is no specific reference to charging for service provision in legislation focused on mental health. In addition, the HSE operates the Drugs Payment Scheme. Under this scheme no individual or family pays more than €134 a month towards the cost of approved prescribed medicines, which includes medications for the treatment of mental health illness.

**Question 3: Please provide information on discrimination against persons with disabilities in the provision of healthcare, health insurance and/or life insurance by public or private service providers.**

*Private Health Insurance in Ireland*

Everyone who is ordinarily resident in Ireland qualifies for public hospital care. Health insurance is optional and people who do not take out health insurance continue to have the same entitlement to services in the public hospital system as everyone else.

Our system of health insurance is community-rated, which means that everybody is charged the same premium for a particular health insurance plan, irrespective of age, gender and the current or likely future state of their health.

A health insurer cannot refuse to provide cover - under Open Enrolment regulations health insurers must accept all applicants for insurance cover, regardless of their risk status, age or sex, subject to prescribed waiting periods.

When an individual takes out health insurance for the first time, they may have to serve waiting periods before they are fully covered (but accident and injury will be covered immediately). The maximum waiting periods are:

|  |
| --- |
| **New Customer Maximum Waiting Periods** |
| Accident and Injuries | Illnesses that commence after you join | Illnesses that commence before you join | Maternity related claims |
| None | 26 weeks | 5 years | 1. weeks
 |

**Question 4: Please provide information on the observance of the right to free and informed consent of persons with disabilities regarding healthcare, including sexual and reproductive health and mental services.**

**The Assisted Decision-Making** (Capacity) Act 2015 was signed by the President on 30 December 2015. The Act reforms Ireland’s Capacity legislation which has been in place since the 19th century. Capacity Assessment - the Act proposes to change the law from the current all or nothing status approach to a flexible functional definition, whereby capacity is assessed only in relation to the matter in question and only at the time in question. If a person is found to lack decision-making capacity in one matter, this will not necessarily mean that s/he also lacks capacity in another matter. The Act recognises that capacity can fluctuate in certain cases.

The Act makes provision for advance healthcare directives. The purpose of the advance healthcare directive is to enable a person to be treated according to their will and preferences and to provide healthcare professionals with important information about the person in relation to their treatment choices. A person may, in an advance healthcare directive, appoint a designated healthcare representative to take healthcare decision on his or her behalf when he or she no longer has the capacity to make those decisions. Designated healthcare representatives will be supervised by the Director of the Decision Support Service.

*Mental Health*

It is a standard and important requirement that consent must be obtained before admitting someone to a healthcare facility, or before offering a person treatment.

There is one exception where a person may be admitted on an involuntary basis to a psychiatric facility in circumstances where it is deemed that the person’s health or life may be in danger or where the person may cause harm to others. In these circumstances, the question of the person’s consent does not arise. The Mental Health Act 2001 provides all the necessary safeguards, such as the right to an independent review of any authorised detention, for people who are admitted on an involuntary basis to ensure that their rights are fully protected.

Specifically, where consent is concerned, however, there is one definition in the Mental Health Act that needs to be amended. Currently, the Act defines a ‘voluntary patient’ as ‘*a person receiving care and treatment in an approved centre who is not the subject of an admission order or a renewal order*’. This definition is regarded as inadequate as it does not mention the need to obtain consent. Amending legislation is well advanced to update this important definition.

**Question 5: Please describe to what extent and how are persons with disabilities and their representative organizations involved in the design, planning, implementation and evaluation of health policies, programmes and services.**

*National Disability Inclusion Strategy 2017 - 2021*

The National Disability Inclusion Strategy (NDIS) was launched by Minister for Disabilities, Finian McGrath TD, on in July 2017.

This Strategy captures a wide range of actions across Government Departments that will impact on the lives of people with disabilities and is to be viewed as a blueprint for an inclusive, accessible and equal country that incorporates issues that affect quality of life, health, education and transport.

Underpinning the Strategy is a vision of an Irish society in which people with disabilities across the lifecycle enjoy equal rights and opportunities to participate in social and cultural life, can work if they want to do so, have choice and control over how they live their lives, and can reach their full potential.

A Steering Group, chaired by Minister McGrath, and comprising key government departments, the National Disability Authority and the Disability Stakeholders Group monitors the implementation of the strategy based on annual work plans, and meets quarterly.

The NDIS contains a commitment for each Department to establish a Disability Consultative Committee (DCC) as part of the monitoring and review process. The Department of Health has established its Committee which is representative of people with disabilities and other key stakeholders. The Committee meets quarterly in advance of each Steering Group meeting.

*26 March 2018*