



Oifig an Cheannaire Oibríochtaí,
Seirbhísí Míchumais Náisiúnta,
An Chéad Urlár - Oifigí 13, 14, 15,
Áras Phlásóg na Rós, Coimpléasc Gnó na hOllscoile,
Páirc Náisiúnta Teicneolaíochta,
Caladh an Treoigh,
Luimneach.

Office of the Head of Operations,
National Disability Services,
First Floor- Offices 13, 14, 15,
Roselawn House, University Business Complex,
National Technology Park,
Castletroy,

9th May 2024

Deputy Marc MacSharry,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: marc.macsharry@oireachtas.ie

Dear Deputy MacSharry,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ 10035/24

To ask the Minister for Children; Equality; Disability; Integration and Youth his views on the level of support for people with muscular dystrophy in Ireland in relation to universal design within higher education institutions; if the Department has any up-to-date data or figures on the number of people in Ireland living with muscular dystrophy; and if he will make a statement on the matter.

HSE Response

HSE Disability Services is allocated funding on an annual basis to provide a range of services throughout the country. Funding is spent in line with nationally agreed policy for disability services, whilst at the same time endeavouring to maximise value. Services include Residential and Respite Services, Day Services, PA and Home Support Services, and Therapeutic Supports.

Disability services are provided based on the presenting needs of an individual rather than by the diagnosis of the individual or the actual type of disability or service required. Services are provided following individual assessment according to the person's individual requirements and care needs.

As the HSE does not collate data based on diagnosis, we cannot provide information regarding the number of people in Ireland living with muscular dystrophy.

The role of the HSE is to provide a multi-disciplinary team approach which includes the provision of health and personal supports required by people with Muscular Dystrophy and incorporates hospital, primary care and community services.



Access Officers promote equality and social inclusion by making sure that persons with disabilities can access public services. This is an important part of creating a society where everyone is treated with dignity, has access to human rights and does not suffer from discrimination.

The role of Access Officers is vital to protecting rights, and for this reason is set out in a law that requires all public bodies as defined by Part 3 of the Disability Act to have an Access Officer. The Disability Act (2005) says that:

“26 (2) Each head of a public body referred to in subsection (1) shall authorise at least one of his or her officers (referred to in this Act as “access officers”) to provide or arrange for and co-ordinate the provision of assistance and guidance to persons with disabilities in accessing its services”.

In order to comply with the Disability Act 2005, the HSE has a network of approximately 238 access officers located throughout the country across community and acute services. Contact details for access officers in the HSE can be found at;

<https://www.hse.ie/eng/services/yourhealthservice/access/accessofficers>.

To support the work of the Access Officers, the HSE published National Guidelines for Accessible Health and Social Care Services in 2014. These Guidelines offer practical guidance to access officers and staff about how they can provide accessible services.

With regard to education, Universal Design in Education (UDE) focuses on a whole system design so that the physical and digital environments, the educational services and the teaching and learning can be easily accessed, understood and used by the widest range of learners and all stakeholders, in a more inclusive environment.

The Centre for Excellence in Universal Design (CEUD) at the National Disability Authority (NDA) has a remit to advance the promotion of Universal Design in education in Ireland. The Authority works to integrate Universal Design as part of education programmes at Primary, Secondary, Third level and CPD Programmes for younger learners also work to recognise the learning by the participating adults.

Integration of the Principles of Universal Design for more accessibility and usability helps to prioritise the needs of people with more diverse abilities, characteristics and preferences, leading to the creation of design solutions that reduce barriers and help enable all people to participate as members of society.

The National Disability Authority statutory remit in respect of third-level education is set down in the Disability Act 2005.

Muscular Dystrophy Ireland

While the HSE and many organisations provide services for people living with Muscular Dystrophy, there are organisations providing specific support for people with Muscular Dystrophy and their family and carers.

Muscular Dystrophy Ireland (MDI) is a voluntary organization which was established in 1972 by a small group of people in the west of Ireland to support families who had a member with muscular dystrophy. Since then it has grown considerably and it now has a membership of over 750 members and a network of support staff throughout Ireland.

MDI's primary objective is to provide support for people and their families who are living with muscular dystrophy and allied neuromuscular conditions.

MDI provides a range of services and supports, including information and support to people with neuromuscular conditions and their families. It also provides accommodation facilities, Family Support Services; Youth Programmes; Respite Services and Summer Respite Camps.



It advocates for services and entitlements for members; educating and informing society about neuromuscular conditions.

It supports researchers and clinicians to carry out quality research into neuromuscular conditions.

The organisation has collaborative partnerships with other organisations, has created an online self-advocacy toolkit and has ran and evaluated annual public awareness campaigns.

There are Service Level Agreements in place between the HSE and MDI for the funding it receives.

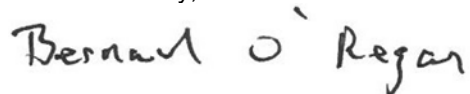
Muscular Dystrophy Ireland works closely with HSE staff at local level in identifying client needs and facilitating access to services

MDI's Information and Display Library is a resource for members of MDI, MDI staff, people with neuromuscular conditions, and educational and health professionals with an interest in neuromuscular conditions. It is also available for people with other neurological conditions and disabilities, students doing special needs projects and other voluntary organisations or agencies.

The Information Service is the first source of assistance for people affected by a neuromuscular condition. It provides information about neuromuscular conditions and other subjects such as benefits, holidays, transport, support groups, genetics etc. Inquiries are received by letter, email or over the telephone from people who have neuromuscular conditions, their family and friends, professionals such as occupational therapists, public health nurses, general practitioners and from members of other organisations.

The Information Officer gathers and disseminates information on the various neuromuscular conditions. They would also keep abreast of all developments in research throughout Europe and America. At the time of diagnosis of a neuromuscular condition, the person with muscular dystrophy and their family will receive basic information about the symptoms and progression of the condition from their medical consultant. Families often find it difficult to absorb all the information they receive at this time and it is recognised by the service that families should have access to information whenever they require it.

Yours sincerely,



Bernard O'Regan
Head of Operations - Disability Services,
Community Operations