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Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
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9th June 2022

Deputy Verona Murphy,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: verona.murphy@oireachtas.ie

Dear Deputy Murphy,

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 26415/22

To ask the Minister for Health if his Department is seeking to secure direct Exchequer funding for the nurses of an association (details supplied) to support motor neurone disease patients and families throughout Ireland; if he will allow for income for the association of which 86% is donations and fundraising to be available for other vital motor neurone disease services and research; and if he will make a statement on the matter.

Details Supplied; Irish Motor Neurone Disease Association (IMNDA)

HSE Response

The Irish Motor Neurone Disease Association (IMNDA) is an organisation working on behalf of people living with Motor Neurone Disease (MND) and their families and carers. Services include home visits by MND nurses, financial assistance towards home help, national freephone service, information on services and allowances and the supply of specialised equipment on loan. MND also fund and promote research into the causes and treatments of MND.

The Irish Motor Neurone Disease Association (IMNDA) is a member organisation of the Disability Federation of Ireland (DFI) which is a national support organisation for voluntary disability organisations in Ireland who provide services to people with disabilities and disabling conditions. DFI provides information, training and support, organisation and management development, research and policy development, advocacy and representation and networking for member organisations.

Motor Neurone Disease (MND) is a progressive neurological condition that attacks the motor neurones, or nerves, in the brain and spinal cord. This means messages gradually stop reaching the muscles, which leads to weakness and wasting. MND affects walking, talking, eating and breathing. Not all symptoms necessarily happen to everyone and it is unlikely they will all develop at the same time, or in any specific order. MND can affect people of all ages and currently there is no cure, however symptoms can be managed and supports provided to help the person achieve the best possible quality of life.

The Irish Motor Neurone Disease Association (IMNDA) is funded by the HSE Disability Services through a grant aid agreement under Section 39 of the health act 2004. The organisation was in receipt of €214,037 in 2021 from the HSE and is set to receive a similar amount from the HSE in 2022.

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The HSE Public Health Nursing Services support people with Motor Neurone Disease and work in partnership with the Irish Motor Neurone Disease Association in respect of specific service users. The HSE also supports hospice services to ensure dignity in end of life care.

The Irish Motor Neurone Disease Association is funded through Community Healthcare Area Dublin North City and County (CHO 9). Any request to change the Terms and Conditions of their funding arrangements with the HSE, must be submitted, in the first instance, in terms of a Business proposal to the Disability Services in CHO Dublin North City and County. The business proposal will be assessed on its merits in the context of the Service Plan, resources and priorities.

Supports provided by Disability Services

The HSE acknowledges the difficulties faced by people who have disabilities due to MND and is providing services with the intention of enabling each individual to achieve his or her full potential and maximise independence, including living as independently as possible. Disability services are provided based on the presenting needs of an individual. Services are provided following individual assessment according to the person's individual requirements and care needs.

As mentioned above, supports can be provided to help the person with symptoms of MND to achieve the best possible quality of life.

As MND is a progressive disease, the needs and requirements of the individual with this disease will change as the disease progresses.

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 Motor Neurone Disease incorporating hospital, primary care and community services.

The HSE funds a range of community services to people with a disability, including persons with Motor Neurone Disease. These include Assisted Living Services, Therapy Services, Respite Care and the provision of Medical/surgical Aids and Appliances.

Therapy Services

People with Motor Neurone Disease can benefit from therapeutic assistance, including Physiotherapy, Occupational Therapy and Speech and Language therapy as well as a range of medical interventions. Therapy services for adults are generally delivered through Primary Care Teams, Community Therapy Services and through specialist adult disability providers.

Aids and Appliances

People with disabilities may be eligible for assistive products that facilitate and/or maintain mobility and/or functional independence.

The HSE provides assistive products to people with disabilities to enable them to maintain their health, optimise functional ability and to facilitate care in their primary care setting.

Assistive products:

- Retain, restore and promote independence
- Empower people to manage their own services or care to the best of their ability i.e. intervene no more than is absolutely necessary.
- Complement existing supports.

Assessments are carried out by a range of multidisciplinary staff, for example assessment and prescription of aids for mobility would generally be carried out by an occupational therapist and/or a physiotherapist.

Respite Services

The HSE and its funded Agencies provide respite care to children and adults with disabilities. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user and their family or carer, and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential placements, preserves the family unit, and supports family stability.

Assisted Living Services

The HSE provides a range of assisted living services including Personal Assistant and Home Support services to support individuals to maximise their capacity to live full and independent lives.

Personal Assistant Services

The role of a Personal Assistant (PA) is to assist a person with a disability to maximise their independence through supporting them to live in integrated settings and to access community facilities.

Services are accessed through an application process or through referrals from Public Health Nurses or other community based staff. Individuals' needs are evaluated against the criteria for prioritisation for the particular service and then decisions are made in relation to the allocation of resources.

Home Support

The Home Support service provides domestic and or personal care inputs at regular intervals on a weekly basis. It differs from the role of a PA in that it focuses more on the necessary domestic and personal care inputs of those based mainly in the home but can occasionally include community activities. Temporary relief is offered to the carer by providing a trained reliable care attendant to look after the needs of the person with the disability.

PA and Home Support Services are provided either directly by the HSE or through a range of voluntary service providers and private for profit providers. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers.

As with every service there is not a limitless resource available for the provision of home support services and while the resources available are substantial they are finite. In this context, services are discretionary and the number of hours granted is determined by other support services already provided to the person/family.

National Neuro-Rehabilitation Strategy

The Implementation Framework for the Neurorehabilitation Strategy was launched on the 20th February 2019, and provides guidance for the development of specialist neurorehabilitation services across the continuum of care – from acute, to post-acute and community services.

Neuro-rehabilitation services play a critical role in supporting recovery and/or maximising ability of those with neurological conditions. We know from our own mapping exercises, that there is a dearth of neuro-rehabilitation services in both inpatient and community levels.

The plan to address this is described within the implementation framework for the Neuro-Rehabilitation Strategy. It outlines a 10-step approach which will see each CHO introducing local implementation teams to oversee and guide the implementation process. It also describes a managed clinical rehabilitation network demonstrator project which is currently progressing through the development of post-acute and community neuro-rehabilitation services across CHO 6 & 7, with full year funding of €2.29m available from 2021. This funding included the establishment of 10 additional in-patient beds on the Peamount Healthcare campus with a complement of 26 staff which is now fully operational. Disability Services Community Healthcare Area 6 are currently working on the recruitment of five therapy posts, capital funding for the service has already been received and the location for the Community Neurorehabilitation Team (CNRT) has been identified. Disability Services Community Healthcare Area 7 are working with Primary Care to identify the

location & governance for the Community Neurorehabilitation Team in this area and will progress to the recruitment of five therapy posts.

Key Messages:

- The introduction of the first Managed Clinical Rehabilitation Network in Ireland is hoped to be the exemplar for the national roll-out of the Neuro-rehabilitation Strategy.
- The project, funded by the SláinteCare Redesign Fund, involves the commissioning of 10 new beds at Peamount Healthcare and introducing Multi-disciplinary teams for CHOs 6 & CHO 7, serving patients with complex presentations who do not require inpatient facilities and those who need to transition from hospital to home.
- These new beds introduce some 3,500 additional specialist rehab bed days per annum into the system.
- With average length of stay of approx. 90 days, this means that 40 patients per annum will have their rehabilitation needs met in an appropriate setting outside of acute hospitals.
- The beds are expected to reduce the NRH waiting list by over 30%, and take direct referrals from AMNCH, SJH, SVUH, Beaumont & the Mater for patients with neurological conditions. The multidisciplinary teams will take referrals from hospitals and the NRH and ensure improved impatient flow and reduced length of stay in the acute setting.

What we want to achieve through this demonstration pilot site MCRN:

- Person centred coordinated approach to patient care
- Development of appropriately resourced interdisciplinary inpatient, outpatient and home and community based specialist rehabilitation teams supported by education and training
- Introduction of the three-tier model of complexity-of-need
- Reduction in Waiting times for assessment and access to inpatient & community rehabilitation services
- Improved patients outcomes and experience
- Standardised pathway for people who require neuro rehabilitation
- Enhanced communication between inpatient and community services to support to delivery of the right care, in the right place, at the right time
- Build up a supporting infrastructure for the demonstration project to deliver neuro rehabilitation to patients as required across the continuum of care
- Develop a model of care that can be rolled out nationally

The learning from this will inform the roll out of the strategy nationally. Implementation of the strategy will lead to improved patient experience and improved patient outcomes for all with neurological conditions.

Yours sincerely,

Bernard O'Regan

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