



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
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6th April 2018

Deputy Seamus Healy,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: seamus.healy@oireachtas.ie

Dear Deputy Healy,

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 14076/18

To ask the Minister for Health if core funding will be made available to an association (details supplied) for its helpline, its advocacy work and to support its branch structure; and if he will make a statement on the matter.

Details Supplied: the Parkinson's Association of Ireland

HSE Response

The Parkinson's Association of Ireland is a charity, based in Dublin with branches throughout the country. Their aim is to assist those with Parkinson's, their families and carers, health professionals and other interested people by offering support and information on any aspect of living with Parkinson's. The organisation promotes and encourages research into Parkinson's and raises awareness through educating the public and health professionals, to give a greater understanding and acceptance of Parkinson's.

The Parkinson's Association of Ireland is largely funded through voluntary contributions and was allocated Grant Aid Agreement in 2018 of €60,000 from Primary Care Services, Community Healthcare Organisation Area 2, (Galway / Mayo / Roscommon) under Section 39 of the Health Act.

National Services include:

- The National Parkinson's Helpline (Freephone 1800 358 359)
- Parkinson's Nurse Specialist education & outreach programme
- Branch network of community volunteers throughout Ireland
- Parkinson's Publications including the quarterly magazine and website www.parkinsons.ie

The HSE liaises with the Parkinson's Association of Ireland through its membership of the Neurological Alliance of Ireland, which is a national umbrella organisation for voluntary groups, professionals and interested parties representing the views and concerns of those whose lives are affected by neurological conditions.

The majority of member groups of the Neurological Alliance of Ireland already receive funding per service provider to approximately €200m per annum. Funding is provided in respect of both operational expenses and service provision. Organisational expenses, funded by the HSE for individual organisations, may include the costs of Chief Executive Officers, administration staff, central office costs, etc. In addition, organisations are funded to provide services to people with disabilities, including the provision of information and support to people with disabilities, the provision of information and expertise to health care professionals working with individuals with particular conditions and, in some cases, the provision of residential, day, respite and all multidisciplinary supports.

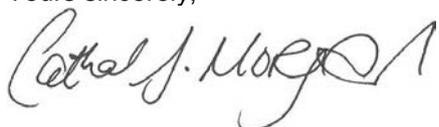
In addition to funding from the HSE, many of the member organisations of the NAI will also receive funding from the Department of Enterprise, Trade and Employment, the Department of Education and Science, the Department of Justice, Equality and Law Reform, the Department of Social Protection and other state agencies.

The HSE also funds the Disability Federation of Ireland to the tune of €1.5m. The role of DFI is to support organisations working with people with disabilities and to represent these organisations to the HSE and to government departments and other state agencies.

We understand that the Neurological Alliance of Ireland is supported, in a structured manner, by DFI, including the staffing and administrative resources of DFI. The HSE supports this approach, whereby DFI, in the context of its role of coordinating and representing voluntary organisations for people with disabilities, supports organisations that have a common interest in the area of neurological conditions.

The HSE recognises the value of the Parkinson's Association of Ireland's services to people with Parkinson's and should further increases in funding be considered this can only be done within the parameters and scope of funding available to the HSE. A process would need to consider where best met funding allocations would reside, such as with Primary Care. At this time, Disability Social Care, in accordance with the National Service Plan 2018, is not in a position to consider further budgetary allocations for 2018. This is a reflection of the significant and current competing demands within the sector to ensure service delivery is maintained.

Yours sincerely,



Dr. Cathal Morgan,
Head of Operations - Disability Services,
Community Operations

Community Supports to People with Parkinson's Disease

The objective of the HSE is to provide a multi-disciplinary team approach which includes the provision of health and personal supports required by people with Parkinson's disease and incorporates hospital and primary care and community services.

The HSE funds a range of community services and supports to enable each individual with a disability, including persons with Parkinson's disease, to achieve their full potential and maximise independence, including living as independently as possible. Services are provided in a variety of community and residential settings in partnership with service users, their families and carers and a range of statutory, non-statutory, voluntary and community groups. Services are provided either directly by the HSE or through a range of voluntary service providers.

Assisted Living Services

The HSE provides a range of assisted living services including Personal Assistant services to support individuals to maximise their capacity to live full and independent lives. While the resources for the provision of assisted living services available are substantial they are finite.

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. The PA works on a one to one basis, in the home and /or in the community, with a person with a physical or sensory disability. A vital element of this personalised support is the full involvement of the individual (service user) in planning and agreeing the type and the times when support is provided to them, supporting independent living must enhance the person's control over their own life.

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. Resource allocation is determined by the needs of the individual, compliance with prioritisation criteria, and the level of resources available.

Services, in the main, are provided either directly by the HSE or through a range of voluntary service providers. The majority of specialised disability provision (80%) is delivered through non-statutory sector service providers.

The HSE is committed to protecting the level of Personal Assistant (PA) services available to persons with disabilities. In the 2018 National Service Plan, the HSE's priority is to provide 1.46 million hours of personal assistance to more than 2,000 people with a disability, representing an increase of 60,000 hours over the 2017 target of 1.4 million hours.

Therapy Services

People with Parkinson's 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 and children are generally delivered through Primary Care Teams or community therapy services; through specialist disability providers or Early Intervention and Children's Teams for 0-18 years, which are continually being developed under *Progressing Disability Services for Children and Young People (0-18s) Programme*.

The HSE has prioritised the development of therapy services in recent years with a range of 484 multi-disciplinary supports, including speech and language therapy, occupational therapy, physiotherapy and psychology, put in place from 2005 to 2009. In 2013, additional funding of €20m was provided to strengthen primary care services. This comprised over €18.5m for the recruitment of over 260 primary care team posts and over €1.4m to support community intervention team development. There was also a €4m allocation within the 2016 Service Plan to facilitate the recruitment of Speech and Language Therapists to address waiting lists as part of the overall Speech and Language Therapy waiting list initiative within Primary Care and Social Care. The allocation provides for an additional 83 posts.

The HSE has commenced the reconfiguration of children's disability services into geographically-based early-intervention and school-aged teams as part of the *Progressing Disability Services for Children and Young People Programme*. The objective of the *Programme* is to provide one clear referral pathway for all children (0-18s), irrespective of their disability, where they live or the school they attend. The transition to this service delivery model is governed by a consultation and engagement process with all stakeholders, including service users and their families, and is being implemented on a phased basis, with full implementation of the model scheduled for 2018.

Since 2014, the roll out of the *Progressing Disability Services for Children and Young People (0-18s) Programme* has entailed targeted investment of €14m and the provision of 275 additional therapy staff, to increase services for children with all disabilities.

National Service Improvement Groups have been established to review Occupational Therapy/Physiotherapy waiting times and the Primary Care Division is working with the Chief Officers in each area to address waiting lists.

The level of increase underlines the commitment of the HSE and Government to ongoing therapy provision. These measures will have a positive impact on the provision of clinical services for all children requiring access to health related supports.

Aids and Appliances

People with disabilities may be eligible for Medical/surgical aids and appliances that facilitate and/or maintain mobility and/or functional independence.

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

Assistive devices such as medical/surgical aids and appliances are provided to individuals to:

- Retain, restore and promote maximum independence
- Empower people to manage their own care to the best of their ability i.e. intervene no more than is absolutely necessary.
- Compensate for the absence of alternative support or complement existing supports.
- Take full account of the risk to the individual if a service is not provided.

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

Prioritisation is based on the results of the assessment and a prioritisation process approves items, which are essential to ensure safety, dignity and independence. All professionals providing community based services, including occupational therapists, physiotherapists, and public health nurses, will be aware of the prioritisation criteria for aids and appliances and will provide any necessary and urgent items of equipment following appropriate assessment as soon as possible.

National Neuro-Rehabilitation Strategy

The HSE and the Department of Health have long appreciated the need to review the situation with regard to access to specialist rehabilitation services. Significant steps toward a resolution were taken with the publication in 2011 of the *National Policy and Strategy for the Provision of Neuro-rehabilitation Services in Ireland 2011-2015*, and the development of the Rehabilitation Medicine Programme within the Clinical Strategy and Programmes Directorate of the HSE.

The National Neuro-Rehabilitation Strategy made a number of recommendations for services for people with rehabilitation needs that covered a range of types of provision including: clinical, therapeutic, social, vocational and community supports.

Following development of the report, the health service as part of its commitment to ensure the optimal care pathway for different Clinical needs, established the Rehabilitation Medicine Programme. Since its establishment, it has been concerned with shaping future specialist rehabilitation services for adults with disability resulting from neurological injury and limb absence across acute, post-acute and primary care settings. The Programme's overall objective is to extend access to specialist rehabilitation services for people with acquired disability so that their ability can be maximised and dependency reduced.

The Rehabilitation Medicine Programme has developed a Model of Care that advocates a framework where patients are managed by specialist rehabilitation clinicians who are connected and supported by the governance structures of a managed clinical rehabilitation network (MCRN). The National Rehabilitation Hospital has been the national hub for specialist rehabilitation for many years and will link formally with proposed new rehabilitation teams in regional centres within each hospital group area and community based neuro-rehabilitation teams within the new Community Healthcare Organisations (CHO's). The new Model of Care will deliver, in line with the 2012 Neuro-rehabilitation Strategy, a blueprint for future provision of specialist rehabilitation services in Ireland.

Outside of the Clinical Programme, the health service Disability Services Division has a role in certain key aspects of Neuro-Rehabilitation Services, primarily the provision of community based therapy services, and personal social services, often funded through partner service providing agencies in the non statutory sector. The Disability Services Division is in the process of implementing "Transforming Lives" the programme to implement the recommendations of the *Value for Money and Policy Review of Disability Services*, and will use

the recommendations of the VFM report, to focus on Disability funded rehabilitation services to encourage reconfiguration of existing provision through the establishment of demonstration sites.

An implementation framework for the demonstration pilot project to enhance neuro rehabilitation community services within the Community Healthcare Organisations CHO 6 & 7, and inpatient specialist rehabilitation services at the National Rehabilitation Hospital, Royal Hospital Donnybrook and Peamount Healthcare has been developed jointly by the HSE Social Care and Clinical Strategy and Programme Divisions. Following a recent meeting arranged by the Minister in the Department of Health the agreed position is, the official publication of this document will take place in Q 2 2018. This time frame has been agreed to allow further consultation with all stakeholders whilst also allowing time to take on board the emerging issues of the demonstration project and apply the learning from this project across all CHO's.

It is recognised that further investment in rehabilitation services at community level is required to progress this implementation framework and provide appropriate services for persons with neurological conditions. In the context of the National Service Plan, the HSE is committed to finalising and progressing the implementation of the framework for neuro-rehabilitation services in Ireland.