Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
Na Seirbhísí Míchumais/An Rannán Cúram Sóisialta,
31-33 Sráid Chaitríona, Luimneach.

Office of the Head of Operations,
Disability Services/Community Operations,
31-33 Catherine Street, Limerick.

T: 00353 (0) 61 483369

12th April 2019

Deputy Maria Bailey,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: maria.bailey@oireachtas.ie

Dear Deputy Bailey,

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 15604/19

To ask the Minister for Health the funding provided by his Department and the HSE since 2016 for the treatment of Parkinson's disease; the payments made to an association (details supplied); and if he will make a statement on the matter.

Details supplied: Parkinson's Association of Ireland

HSE Response

The Parkinson's Association of Ireland is largely funded through voluntary contributions and was allocated Grant Aid Agreement in 2019 of €60,000 from HSE 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.

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.

Funding (The tables below outline the information available to us regarding funding from the HSE)

Year 2019		Area	Funding source	Amount
Parkinson's Association Galway S 39	Grant Aid Agreement	CHO 2	Primary care	€40,000
Parkinson's Association Mayo S 39	Grant Aid Agreement	CHO 2	Primary Care	€ 20,000

Year 2018		Area	Funding source	Amount
Parkinson's Association Galway S 39	Grant Aid Agreement	CHO 2	Primary care	€40,000
Parkinson's Association Mayo S 39	Grant Aid Agreement	CHO 2	Primary Care	€ 20,000

Year 2017		Area	Funding source	Amount
Parkinson's Association Galway S 39	Grant Aid Agreement	CHO 2	National Lottery	€5,000
Parkinson's Association Area 9 S 39	Grant Aid Agreement	CHO 9	National Lottery	€ 12,050

Year 2016		Area	Funding source	Amount
Parkinson's Association Area 9 S 39	Grant Aid Agreement	CHO 9	Primary Care	€ 8,700

Services provided to people with disability due to 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. The facilities and options available for persons with Parkinson's disease are outlined below.

Assisted Living Services

The HSE provides a range of assisted living services including Personal Assistant (PA) and Home Support services to support individuals to maximise their capacity to live full and independent lives. These are related but separate

services and each is funded separately. While the resources for the provision of assisted living services available are substantial they are finite.

PA and Home Support Services 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.

PA 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. 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.

Home Support Services

The Home Support service provides domestic and or personal care inputs at regular intervals on a weekly basis. 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. The service provides support to the parents to enable them to spend quality time with the other siblings in the family: it also supports the individual with the disability in terms of their care plan with particular attention in the personal needs of the individual. Home supports can be provided through a dedicated home support service or through the generic home help service. Home supports can be an alternative to residential care, where support to individuals in daily living can avoid the need for full time residential services.

Accessing Services

Services are accessed through an application process or through referrals from public health nurses or other community based staff. Individual's needs are evaluated against the criteria for prioritisation for the particular services 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. 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.

The HSE is committed to protecting the level of Personal Assistant (PA) services and Home Support services available to persons with disabilities including those who have disability as a result of Parkinson 's disease.

Therapy Services

People with disability as a result of stroke 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.

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.

There will be improvement in access to primary care occupational therapy services with a focus on addressing patients waiting over 52 weeks, through the appointment of 40 occupational therapists. The recommendations from the reviews of the primary care physiotherapy, occupational therapy and speech and language therapy services will be implemented on a phased basis.

Aids and Appliances

People with disability as a result of stroke may be eligible for Medical/surgical aids and appliances that facilitate and/or maintain mobility and/or functional independence and are responsive to a person's presenting needs at any given time. These assistive devices enable people with a disability to maintain their health and to optimise functional ability.

National Neuro-Rehabilitation Strategy

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

The overarching aim is the development of population based managed clinical rehabilitation networks around the country. For this to happen, there will need to be investment in rehabilitation services across the continuum of care.

There are three recognised levels of specialist rehabilitation described for the Irish context (from NCPRM, adapted from the British Society of Rehabilitation Medicine (BSRM):

- Complex Specialist Service
- Specialist Inpatient Rehabilitation Services
- Community Rehabilitation Services

From a mapping exercise undertaken in 2017, we know that the most significant gaps are with respect to local specialist inpatient rehabilitation services and community specialist neurorehabilitation service. In terms of Complex Specialist Service, the National Rehabilitation Hospital (NRH) fulfils this role currently. The NRH has 108 inpatient beds at present with an increase to 120 beds once the new hospital development is complete.

While we know the ideal staffing ratios for neurorehabilitation services per service setting (based on BSRM standards), what is not known currently is what existing services may be amenable to reconfiguration. As such, the costings outlined below are total maximum costings and do not take into account any potential reconfiguration.

In line with the current British Standards for Rehabilitation Medicine (BSRM) recommendations for specialist rehabilitation service provision in Ireland and in keeping with the hub and spoke model outlined in the Neuro-Rehabilitation Strategy, there is a need for the development of at least 60 beds per million population for specialist in-patient rehabilitation medicine i.e. 288 for Irish population. The cost of staffing a 20-bed inpatient unit, based on BSRM recommended staffing ratios is € 4,116,717 – including non-pay costs. This figure would need to be multiplied by approximately 14.5 to give the figure for the required 288 beds. This figure does not take in to account capital costs. Again, it is important to note that this is the figure for introducing a whole new service – i.e. with no reconfiguration of existing staff.

Recommended staffing ratios for the provision of community neurorehabilitation services are also adapted from the recommendations by the British Society of Rehabilitation Medicine (BSRM). These are the ratios recommended within the recently published Model of Care of the National Clinical Programme for Rehabilitation Medicine. The BSRM ratios are given per population of 1 million. These figures have been adapted based on population per CHO so specific staffing numbers may vary across CHOs depending on population. The cost of a new Community Neurorehabilitation Team serving a population of approx 500,000, including non pay costs would be €5,180,609. Again, this does not take in to account any reconfiguration of existing staff, nor does it include any potential capital costs.

The costs associated with the MCRN demonstrator project have been divided into phase 1 and phase 2. The associated costs include:

(a) a community neurorehabilitation team in both CHO 6 & 7.
(b) development of inpatient neurorehabilitation services at both Royal Hospital Donnybrook and Peamount.
(c) enhancement of services at the National Rehabilitation Hospital.

The cost for phase 1 is estimated at €4,585,214 and phase 2 is estimated at €7,738,332. Again, these figures are inclusive of non-pay costs.

The 2019 HSE National Service Plan makes no provision for funding to commence the Implementation Framework,

On 22nd March 2019 the Taoiseach and Minister for Health welcomed the launch of the €20m Slaintecare Integration fund and the previous submission for funding will now be resubmitted in the format required. While we await the

outcome of funding submissions, the relevant stakeholders are working together to maximise the use of the existing resources for the benefit of people who require rehabilitation supports.

Yours sincerely,

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