



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
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13th April 2021

Deputy Alan Kelly,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: alan.kelly@oireachtas.ie

Dear Deputy Kelly,

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 16766/21

To ask the Minister for Health the way in which his Department plans to meet the needs of persons with spina bifida and hydrocephalus in order that they can live independently with access to adequate supports, for example, occupational therapy and neuropsychology services instead of persons ending up in nursing homes from the age of 30; and if he will make a statement on the matter.

HSE Response

Spina Bifida Hydrocephalus Ireland

Spina Bifida Hydrocephalus Ireland (SBHI) was established in 1968 by a small group of parents whose children had Spina Bifida and/or Hydrocephalus. The association represents over 8,000 people nationwide consisting of those with Spina Bifida and/or Hydrocephalus, their parents, siblings, family, friends and carers.

The purpose of Spina Bifida Hydrocephalus Ireland is to provide information, support and advice to people with Spina Bifida and/or Hydrocephalus, their parents and carers, as well as to promote social inclusion and equality for people with Spina Bifida and/or Hydrocephalus in Irish society.

The HSE provides funding to Spina Bifida Hydrocephalus Ireland (SBHI) under Section 39 of the Health Act 2004. This amounted to €781,574 in 2020. A service level agreement between HSE and SBHI is in place.

SBHI provides Family Support Workers (FSW) nationally to individuals with Spina Bifida and/or Hydrocephalus, their families, carers and professionals. The Service works with members from time of diagnosis through to adulthood, providing guidance, advocacy, emotional and practical support. The FSW team also works with healthcare professionals, education professionals and those working within the disability sector by providing information, resources and guidance.

In addition, the HSE also provided funding of €127,512 in 2020 to the Mid West Spina Bifida and Hydrocephalus Association under Section 39 of the Health Act.

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 Spina Bifida 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 Spina Bifida, to achieve his or her 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. These services include Assisted Living Services, Therapy Supports and Aids and Appliances.

With regard to persons with spina bifida and hydrocephalus residing in Nursing Homes, Disability services endeavour to support and enable people with disabilities to live as far as possible the life of their choosing in their own homes and communities, through services, supports and environments, designed and adapted as necessary to meet their needs, enabling them to live ordinary lives in ordinary places as independently as possible.

In addressing the needs of young disabled adults, the full range of community services available are tailored to meet the needs of the individual. The health service works with local authorities, the Department of Education and Skills and other public services as well as the voluntary sector in seeking to tailor the services to best fit the needs of the individual.

The Nursing Home sector is used in developing options to meet the needs of young adults with a disability where no other alternatives are possible to meet their care needs. In the longer term, the policy is to develop a more tailored service suitable to meet the needs of these service users.

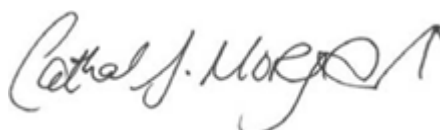
All persons admitted to Nursing Home Care must satisfy a multi-disciplinary assessment to establish that they require 24 hour nursing care. Therefore, persons are assessed taking into consideration their capacity or capability to carry out the 'activities of daily living' – rather than being admitted to nursing homes on the basis of having a particular condition.

Some of the younger people in Nursing homes may have mental health issues or co morbidity complex medical conditions which may or may not include spina bifida hydrocephalous which require 24 hour nursing care which the community is not resourced to provide.

The HSE is aware that of those being cared for in a nursing home, there are a number of people with a disability who wish to live independently with the appropriate supports. The HSE, working with the Community Healthcare Organisations, makes every effort to accommodate people's wishes and support them to move to the home of their choice with support based on assessed need. However, and in accordance with the HSE's National Service Plan, resources are finite and regrettably, people will sometimes have to wait a period of time before their wish can be facilitated.

It must also be noted however, that the HSE National Service Plan 2021, in response to current and demographic need, provides for 18 places to support people with disability under the age of 65 to move from nursing homes to their own home in the community

Yours sincerely,



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