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20th May 2020

Deputy Cian O'Callaghan,
Dáil Éireann,
Kildare Street
Dublin 2

PQ Number: 5204/20

PQ Question: To ask the Minister for Health his plans for dedicated Huntington's disease clinics, staffing and funding; if his attention has been drawn to the inappropriate placing of younger persons with neurological conditions in nursing homes; and if he will make a statement on the matter. – Cian O'Callaghan

Dear Deputy O'Callaghan,

Huntington's disease is a rare neurological condition. Patients with Huntington's disease are followed as part of the international ENROLL HD programme, with centres in Dublin and Galway. The National Clinical Programme for Neurology recognizes the importance of specialist clinics for rare diseases, and has developed a framework for national specialist multidisciplinary services using Motor Neurone Disease as an initial model. Similar clinics for Huntington's disease are envisaged as part of a 5 year programme, aligned to the objectives of Sláintecare.

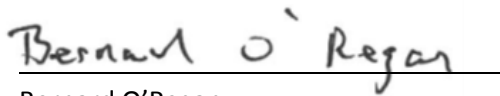
With respect to rehabilitation for those with Huntington's disease, the Implementation Framework for the Neurorehabilitation Strategy was launched on the 20th February 2019, and provides guidance for the development of specialist neurorehabilitation services across the continuum of care – from acute, to post-acute and community services.

The implementation framework is based on a 10-step approach pioneered by the Integrated Care Programme for Older People. This is a scientific approach based on data including population needs assessment, mapping of existing services, analysis of gaps in current services in line with benchmarked best practice. The ultimate goal of this approach is to put in place a national framework of acute, inpatient and specialist community neurorehabilitation service to meet the rehabilitative needs of those with Neurological Conditions.

With respect to residential services, we are aware that there are a number of people with disabilities who are under 65 and placed in nursing homes. We are aware also that the Ombudsman is looking into

the issue also. In line with the *Time to Move on from Congregated Settings – A strategy for Community Inclusion* report, our hope is to enable these people to move from inappropriate settings to their own homes in the community with the support they need or more appropriate long-term care facilities based on their need.

Yours sincerely,

A handwritten signature in black ink that reads "Bernard O'Regan". The signature is written in a cursive style and is positioned above a horizontal line.

Bernard O'Regan

Head of Disability Strategy and Planning