



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

15th June 2020

Deputy Noel Grealish,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
e-mail: noel.grealish@oireachtas.ie

Dear Deputy Grealish,

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 8797/20

To ask the Minister for Health the number of children that have a severe or profound disability; and if he will make a statement on the matter.

HSE Response

The Health Service Executive does not currently collate records on children that have a severe or profound disability. Disability services are provided based on the presenting needs of an individual rather than by the diagnosis of the individual or the actual type of disability or service required. Services are provided following individual assessment according to the person's individual requirements and care needs. Care and/or services provided are tailored to the individual needs and requirements of the child/adult with profound sensory disabilities.

However, the Health Research Board (HRB) which manages five national information systems has compiled data from two national service-planning databases for people with disabilities on behalf of the Department of Health: the National Intellectual Disability Database (NIDD), established in 1995, and the National Physical and Sensory Disability Database (NPSDD), established in 2002. These databases have informed decision-making in relation to the planning of specialised health and personal social services for people with intellectual, physical, sensory, neurological or speech or language disabilities.

The NIDD is currently being replaced by the National Ability Support Services (NASS) Database and therefore the most recent figures published by the Health Research Board (HRB) relate to 2017 and show that there were 28,388 people registered on the NIDD at the end of December 2017. The number of children (0 to 19 yrs) registered on NIDD recorded as having moderate, severe or profound intellectual disability was 10,032 (3,311 girls and 6,721 boys).

However, participation in the database is voluntary and therefore not every individual in Ireland, who has a disability, consents to inclusion on the database. Therefore, the database does not provide any definitive epidemiological statement on the number of people with a particular type of disability or

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diagnosis, nor does it cover the proportion of people living in Ireland who have a disability and have chosen not to register.

This information was obtained from the Health Research Board (HRB) Statistics Series 37, Annual Report of the National Intellectual Disability Database Committee 2017, Main Findings. This information is accessible at; <https://www.hrb.ie/publications/>

Yours sincerely,



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