



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Oifig an Cheannaire Oibríochtaí,
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17th November 2021

Deputy Malcolm Noonan,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: malcolm.noonan@oireachtas.ie

Dear Deputy Noonan,

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 53731/21

To ask the Minister for Health the number and names of residential service providers that have established family forums; the steps taken by his Department and the HSE to support residential support providers establish family forums; his views on the effect of the family forums on the quality of life of day service users, residents and their families; and if he will make a statement on the matter.

HSE Response

The statutory right of persons who avail of Intellectual Disability Services to participate in the organisation of their service is recognised by the HSE.

The following outlines the HSE position on engagement with service users and the relevant statutory requirements:

- Healthcare Act, 2007 – (Care and Support of residents in Designated Centres for Persons (Children and Adults) with disabilities) Regulations 2013 – Regulation 5 (4) and Regulation 9 (2)
- The HIQA *National Standards for Children and Adults with Disabilities* (HIQA, 2013)
- *Framework for Improving Quality in our Health Service* (HSE, 2016), sets out engagement with the person and family as one of the key drivers for quality improvement.
- The Social Care Divisional *Operational Plan 2017* identifies consultation with people who use services as a key objective.
- *Transforming Lives Programme*: This is a programme to implement the recommendations of the 'Value for money and policy review of the disability services in Ireland' (2012). Through this group a number of working groups have been set up to implement the recommendations. Working Group 3 has a clear objective of developing guidelines for service user participation in decision making process.
- Progressing Disability Services for Children and Young People, National Guidance for Local Implementation Groups and Children's Disability Services on Family Forums 4.12.15. In accordance with the Guidelines for local implementation groups on developing a governance structure and policies for children's disability services the governance group should have a minimum of two family representative members.

In addition, the HSE has supported the provision of Family Forums with The Social Care Division

Intellectual Disability Residential Service, Allocated Service Framework for the Development of a Residents Forum. This framework which was developed by the National Disability Services, Quality Improvement Team in 2017, outlines the principals and steps that need to be considered when developing a Residents Forum in residential services within an Allocated Service area. This document was widely circulated for use in residential centres. The document can also be adapted when setting up forums in other types of services, for example, day services.

Referring again to Residential Services and the HIQA National Standards for Children and Adults with Disabilities (HIQA, 2013) the following is outlined:

Standard 1.3: Each person exercises choice and control in their daily life in accordance with their preferences.

1.3.4 The everyday activities of the residential service vary according to people's interests and activities. They take account of different levels of functioning and ability and of each person's personal plan. People are encouraged to:

- contribute ideas to, and participate in, the day-to-day activities of the service
- participate in residential committees and fora
- are represented in whatever forum is used to discuss and plan the future direction of the service.

An individual's representative can also participate. This representative is the person, preferably nominated by the individual, who acts on their behalf in situations where the individual lacks capacity to make decisions. This person will often be a family member and could also be a friend, advocate or legal advisor. The role of this person is to ascertain, as far as possible, the individual's wishes and to act in every instance in the individual's best interests.

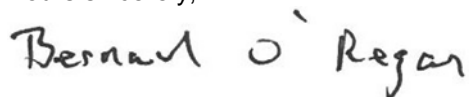
HIQA's Guidance on the assessment of fitness for designated centres (Jan 2018) states that the provider must demonstrate the governance arrangements they have in place to include a responsive quality assurance framework. Arrangements should also confirm resident and family forums, complaints and incident management processes.

By the end of 2020 there were 1,340 registered designated centres for people with disabilities in the Republic of Ireland. These centres provide residential and respite services for over 8,700 people with disabilities

HIQA's Disability inspection teams are legally responsible for the monitoring, inspection and registration of designated centres for adults and children with a disability. All residential centres are inspected against the National Standards and Health Regulations including the centres' provision of residents, committee or family forums. As Registration is for a period of three years, the vast majority of these centres will have been through the registration process twice.

The HIQA report of the first five years of regulation of HSE or HSE funded designated residential centres for adults and children with disabilities in Ireland, published in July 2019, showed that year on year compliance with HIQA regulations was extremely positive with sustained improvements from 34% in early 2014 to 76% compliance by 2018. The most recent HSE Report indicates a compliance rate of 92% in 2020.

Yours sincerely,



**Mr Bernard O'Regan,
Head of Operations - Disability Services,
Community Operations**