



Oifig an Stiúirthóir Cúnta Náisiúnta,
Foireann Míchumais Náisiúnta,
An Chéad Urlár - Oifigí 13, 14, 15,
Áras Phlásóg na Rós, Coimpléasc Gnó na hOllscoile,
Páirc Náisiúnta Teicneolaíochta,
Caladh an Treoigh,
Luimneach.

Office of the Assistant National Director,
National Disability Team,
First Floor- Offices 13, 14, 15,
Roselawn House, University Business Complex,
National Technology Park,
Castletroy,
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14th May 2024

Deputy Catherine Murphy,
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
E-mail: catherine.murphy@oireachtas.ie

Dear Deputy Murphy,

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: 18914/24

o ask the Minister for Children; Equality; Disability; Integration and Youth the obligations on disability service providers for adults to operate family committees and forums for families to share their views on aspects of service provision.

HSE Response

Specialist disability services focus on providing supports to people with more complex disabilities throughout life, and on complementing the mainstream health and social care services provided. The primary goal of disability services is to improve access for children and adults to essential health and social care services that support people to have equity of opportunity to maximise their potential of living a life with choice and control.

The HSE works in partnership with organisations including Section 38, Section 39, Out of State and For Profit organisations to ensure the best level of service possible is provided to people with a disability, and their families, within the available resources. The majority of specialised disability provision is delivered through non-statutory sector service providers.

As per the National Service Plan 2024, the HSE in partnership with Service Providers, will enable people with disabilities to be active participants in their care and support. The Transforming Lives programme includes the main policies underpinning the development of disability services including New Directions, Progressing Disability Services for Children and Young People, Time to Move on from Congregated Settings – A Strategy for Community Inclusion, personalised budgets and the Neuro-Rehabilitation Strategy. It also frames the development of important enabling actions including the inclusion of disabled people in decision-making and underpins the collaborative working between the HSE and the voluntary sector.



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

The following outlines some of the relevant statutory requirements, policies and guidelines regarding engagement with service users:

- 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.
- *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.

In addition, the HSE has supported the provision of Family Forums with the 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, 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.

With regard 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.

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.

HIQA published a Disability Services Residents Forum Meetings Report in December 2022. Using Residents' Forums, HIQA was provided with information regarding what is like for residents living in Residential Centres. Inspectors gathered feedback from residents about their home, the support they receive and the important areas that inspectors should be looking at when they are on inspection.

Please see:

<https://www.hiqa.ie/hiqa-news-updates/residents-disability-services-tell-hiqa-about-their-right-have-their-voices-heard>

In addition to the above, the HSE funds and supports advocacy services for people with disabilities.



Several advocacy organisations including Inclusion Ireland, Disability Federation of Ireland (DFI) and the National Federation of Voluntary Service Providers receive funding to ensure that the voices of people with disabilities are heard when it comes to changes in services and legislation that will improve the quality of life and participation of people with a disability in Irish Society.

Many other non statutory agencies, funded by the HSE also have a role in upholding and protecting the rights and dignity of people with disabilities, although this may not be their primary role and functions.

The role of service users through advocacy in informing health and personal social services provision is well documented. Effective service user involvement enables services to anticipate problems, avoid complaints, develop appropriate and effective service provision and it guarantees that service users will be at the centre of efforts to improve the quality and safety of service provision for many years to come.

The Connect Family Network

The HSE has engaged Inclusion Ireland to establish a national network of family support groups in the disability sector; the Connect Family Network. The Connect Family Network will endeavour to bring about greater participation of persons with a disability and their family members in the design and delivery of disability services and supports.

Research has shown that service and policy development is much more effective when the people who use services are involved from the outset.

The Connect Family Network will not replace any organisation, but will aim to enable a coherent and combined family voice to be heard by service providers and policy makers. Supports to family support groups will include information provision, facilitation of networking opportunities, capacity building training and support for families to have their voices heard in policy formation and implementation.

The HSE has also commissioned SAGE to pilot a Disability Advocacy model of service in Community Healthcare Organisation Area 5.

National Platform for Self Advocates

The National Platform for Self Advocates is an independent advocacy organization which was set up as a forum for people with Intellectual Disability. Inclusion Ireland facilitated the process of setting up this national platform, although it has its own unique identity and is outside the remit of agencies involved in direct service provision. One of the roles of the Platform was to disability proof national policy from an intellectual disability perspective.

The HSE supports the work of the National Platform for Self-Advocates, but is also very conscious of the need to deliver disability policy on a more sustainable footing given the significant levels of need for increased and more effective services and supports to enable people with a disability to live independent lives in their own community. Hence, it is important that organisations such as the National Platform for Self-Advocates look to other funding streams such as the Department of Rural and Community Development's Scheme for Community and Voluntary Organisations. The HSE understands that funding of €18.5m over the coming three years has been approved for this Scheme.

Dialogue Forum with Voluntary Organisations

The Partnership Principles was launched on the 3rd April 2023 by Government, the HSE and the Voluntary Organisations.

The Dialogue Forum with Voluntary Organisations was established in late 2019 with the aim of building a stronger, more collaborative, working relationship between the State and voluntary providers (S38/39) in the health and social care sector for the benefit of the people using our health services. Members of the Forum include the Department of Health, HIQA, Mental Health Commission and 8 voluntary representative organisations.

To facilitate regular and structured dialogue between these entities, the Forum has engaged in several activities, including the collaborative development of the Partnership Principles, which serve as a foundation for strengthening the relationship between the State and voluntary organisations. The Principles emphasise the need to place the person at the centre of our partnership and to work on the basis of trust and mutual respect so that coherent planning and good



decisions are informed by engagement and participation - harnessing the strengths of both the statutory and voluntary sectors for the benefit of the people using our services.

Yours Sincerely,

Bernard O'Regan

Bernard O'Regan
Assistant National Director
National Disability Team

