

Oifig an Stiúrthóir Cúnta Náisiúnta,

Foireann Míchumais Náisiúnta, An Chéad Urlár - Oifigí 13, 14, 15, Àras 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, Limerick.

1st October 2024

Deputy Holly Cairns, Dail Eireann, Leinster House, Kildare Street, Dublin 2.

E-mail: holly.cairns@oireachtas.ie

Dear Deputy Cairns,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary questions, which were submitted to this department for response.

PQ: 36080/24

To ask the Minister for Children; Equality; Disability; Integration and Youth if guidance has been issued from his Department to providers of respite services in relation to including or excluding specific details of respite care in annual contracts with those who are offered respite care; if so, to provide this guidance; and if he will make a statement on the matter.

HSE Response

The HSE and its funded Agencies provide respite care to children and adults with disabilities. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user and their family or carer, and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential placements, preserves the family unit, and supports family stability.

The provision of residential respite services has come under increasing pressure in the past number of years due to a number of impacting factors such as:

- an increase in the number of children and adults who are seeking access to respite as a reflection of general population increase;
- increasing levels of complexity across the sector due to better and improved health care;
- an increase in the age of people with a disability resulting in people presenting with "changing needs";
- a significant number of respite beds have been utilised on longer-term basis due to the presenting complexity of the individual with a disability and also due to home circumstances, which prevents availability of the bed to other respite users;



- the regulation of service provision as set by HIQA, which requires Service Providers to comply with regulatory standards in order to meet regulation. Standards specify a requirement for personal and appropriate space which impacts on the capacity and Statement of Purpose for a Designated Centre. This has had a direct impact on capacity where respite beds are no longer allowed within a residential setting e.g. vacated by residents who go home at weekends or for holidays, can no longer be used for respite.
- Implementation of the national policy on congregated settings (Time to Move on from Congregated Settings Policy) is also affecting capacity.

Respite Provision

Governance Framework for Funded Agencies (Framework)

The HSE funds and works in partnership with organisations including Section 38, Section 39, Out of State and For Profit Agencies (Agencies) to ensure the best level of service, including respite services is provided to people with a disability, and their families, within the available resources.

Regardless of the type of organisation or its location, there are mechanisms, safeguards and procedures in place to provide assurances to the HSE and to support accountability processes for public expenditure on health and personal social services.

The HSE must have in place appropriate contractual arrangements Service Arrangements (SA) and Grant Aid Agreements (GA) with all Agencies that have funding released to them for the provision of services.

The Framework was introduced to implement the legislative provisions of the Health Act, 2004 and to reflect the requirements for public accountability where the HSE is legally obliged to account for all public expenditure on health and personal social services. In this regard, the SA is a key document which comprises of Part 1 and Part 2 service Arrangements

The Framework seeks to provide a level of governance which links funding provided to a quantum of service and provides for these services to be linked to quality standards, with continuous monitoring to ensure equity, efficiency and effective use of available resources.

The Service Arrangements outlines the requirements that must be met by the Service Provider for the provision of services.

The Part 2 Service Arrangement states that agencies must download and review the list of requirements and are required to comply with all relevant regulation and must ensure they have the appropriate structures and systems to be aware of any updates as relevant to the organisation. This can be found at:

https://www.hse.ie/eng/services/publications/non-statutory-sector/policies-procedures-guidelines-codes-of-practice-legislation.html

The listing is provided as an aid to Agencies in accessing the pertinent statutory regulation, codes of practice, standards and quality assurance programmes applicable under the Service Arrangement, it is not an exhaustive listing and Providers must ensure that they have adequate systems in place to identify and comply with all their Legal, Regulatory and professional responsibilities with regards codes of practice, standards and quality assurance requirements in the delivery of the services.

Person Centred Services

The listing mentioned above includes the *Guidelines on Person Centred Planning in the provision of Services for People with Disabilities in Ireland (NDA)*.

This document, on person centred planning in the provision of services to people with disabilities, is useful to service providers in setting out the values and principles which underlie person centred planning and the essential elements of its overall approach, required context and associated methodologies.



It is mainly intended to provide information and support to services supporting the development and/or realisation of person centred plans, though it is also intended to provide information for people with disabilities and their parents, families, friends, spouses and advocates which will help them understand what is meant by person centred planning.

This is available at:

https://nda.ie/publications/guidelines-on-person-centred-planning-in-the-provision-of-services-for-people-with-disabilities-in-ireland

The HSE's National Framework for Person-Centred Planning in Services for Persons with a Disability includes information on developing an adequate system of communication that is fully accessible to all parties likely to be involved in the person centred planning process. People with disabilities, their parents/families, friends and advocates must be actively involved.

This is available at:

https://www.hse.ie/eng/services/list/4/disability/newdirections/person-centred-planning/

National Standards for the Provision of Services.

The Health Information and Quality Authority (the Authority) aims to promote progressive improvements in quality and safety of residential services provided to children and adults who use services on either a long-term or short-term basis.

These National Standards apply to residential services and residential respite services in Ireland, whether they are operated by public, private or voluntary bodies or organisations.

They provide a framework for providers for the ongoing development of person-centred residential services for all people with disabilities including those with intellectual disabilities, physical and sensory disabilities and autism.

The Standards also provide those who use services and their families/representatives with a guide as to what they should expect from residential services.

Under Standard 2:1, Each person has a personal plan which details their needs and outlines the supports required to maximise their personal development and quality of life, in accordance with their wishes.

Also Standard 2.1.4 states: To ensure there is a single integrated plan, the personal plan takes account of:

- an assessment of the person's abilities, skills and needs, carried out with appropriate professional assistance, if required and requested
- other specific plans such as health plans, risk management plans, intimate support plans.

Standard 2.1.5 states: Each person has a copy of their personal plan in an accessible format.

For more information regarding the Standards and what is required from Providers of Residential and Residential Respite services, please see:

https://www.hiqa.ie/reports-and-publications/standard/national-standards-residential-services-children-and-adults

Regulation

Residential and Residential Respite centres are prescribed as 'designated centres' in the Health Act 2007. The Health Information and Quality Authority has, among its functions under law, responsibility to regulate the quality of service provided in designated centres for people with disabilities.

The purpose of regulation in relation to designated centres is to safeguard people with disabilities who are receiving residential services. Regulation provides assurance to the public that people living in designated centres are receiving services and supports that meet the requirements of national standards which are underpinned by regulations.

Regulation has an important role in driving continuous improvement so that people with disabilities have better, safer lives. When a designated centre does not meet the required standards and/or the provider fails to address the specific



areas of non-compliance, appropriate enforcement action is taken to either control or limit the nature of the service provided, or, to cancel a centre's registration and prevent it from operating.

As part of the registration and onward process of regulation, the provider must satisfy the Chief Inspector that s/he is fit to provide the service and that the service is in compliance with the Act, the Regulations and these or other specified standards.

Part 2 of S.I. No. 367/2013 - Health Act 2007 (Care and Support of Residents in Designated Centres for Persons (Children and Adults) with Disabilities) Regulations 2013, provides for the Maintenance, Care, Support and Well-being of Persons Resident in a Designated Centre.

In particular it refers to individualised assessment and personal plan as follows:

- 5. (1) The person in charge shall ensure that a comprehensive assessment, by an appropriate health care professional, of the health, personal and social care needs of each resident is carried out—
- (a) prior to admission to the designated centre; and
- (b) subsequently as required to reflect changes in need and circumstances, but no less frequently than on an annual basis.

This is available at:

https://www.irishstatutebook.ie/eli/2013/si/367/made/en/print

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Yours Sincerely,

Bernard O'Regan

Assistant National Director National Disability Team

