



**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

Health Information  
and Standards

# The characteristics of person-centred care in residential services for children and adults with disabilities: a scoping review protocol

May 2025

## About the Health Information and Quality Authority (HIQA)

The Health Information and Quality Authority (HIQA) is an independent statutory body established to promote safety and quality in the provision of health and social care services for the benefit of the health and welfare of the public.

Reporting to the Minister for Health and engaging with relevant government Ministers and departments, HIQA has responsibility for the following:

- **Setting standards for health and social care services** — Developing person-centred standards and guidance, based on evidence and international best practice, for health and social care services in Ireland.
- **Regulating social care services** — The Chief Inspector of Social Services within HIQA is responsible for registering and inspecting residential services for older people and people with a disability, and children's special care units.
- **Regulating health services** — Regulating medical exposure to ionising radiation.
- **Monitoring services** — Monitoring the safety and quality of permanent international protection accommodation service centres, health services and children's social services against the national standards. Where necessary, HIQA investigates serious concerns about the health and welfare of people who use health services and children's social services.
- **Health technology assessment** — Evaluating the clinical and cost effectiveness of health programmes, policies, medicines, medical equipment, diagnostic and surgical techniques, health promotion and protection activities, and providing advice to enable the best use of resources and the best outcomes for people who use our health service.
- **Health information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information on the delivery and performance of Ireland's health and social care services.
- **National Care Experience Programme** — Carrying out national service-user experience surveys across a range of health and social care services, with the Department of Health and the HSE.

Visit [www.hiqa.ie](http://www.hiqa.ie) for more information.

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## 1. Introduction

It is estimated that 16% of the global population (1.3 billion people) experience disability.<sup>(1)</sup> In the European Union, this figure is estimated to be 101 million, with over one million people living in institutions.<sup>(2,3)</sup> In 2022, almost 74,000 people with a disability were engaging with a disability service in Ireland. Of those, 7,486 people were reported to be living in a residential service, while overnight respite was provided to 3,196 people.<sup>(4)</sup>

The World Health Organization (WHO) *Global report on health equity for persons with disabilities* published in 2022 stated that people with disabilities have an equal right to the highest attainable standard of health. However, despite substantial progress in many countries, there is still disparity in the standard of care, owing to the persistent health inequities that persons with disabilities experience.<sup>(1)</sup>

Service delivery has shifted from a system-centred approach to a person-centred approach in the last few decades.<sup>(5)</sup> Person-centred care is a holistic approach to care, in which people are provided with the support needed to enable them to participate and make decisions about their own care, and care is tailored to their individual needs.<sup>(6)</sup> A person-centred approach to care has been shown in some studies, to have many positive benefits delivering better outcomes for those receiving care, including people with disabilities.<sup>(6,7)</sup> However, a systematic review in 2016 on the effectiveness of person-centred planning for people with intellectual disabilities concluded that clearer descriptions of person-centred planning and its components are needed.<sup>(8)</sup>

Setting national standards is a quality improvement intervention deemed effective in establishing consistency in the delivery of high-quality care.<sup>(9)</sup> National standards for health and social care promote practice that is up to date, evidence-based and effective.<sup>(10)</sup> In Ireland, the Health Information and Quality Authority (HIQA), is an independent statutory authority established to promote safe, high-quality care for people using health and social care services.<sup>(11)</sup> Informed by evidence and best international practice, HIQA has statutory responsibility for setting standards for health and social services and has a role in checking compliance against those standards.<sup>(11)</sup>

In 2013, HIQA published *National Standards for Residential Services for Children and Adults with Disabilities*. Since then, there have been significant legislative advancements, with an increased focus on a human-rights based approach to care, including the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) in 2018 and the commencement of the Assisted Decision-Making (Capacity) Act 2015.<sup>(12,13)</sup> As a result of these legislative changes, the

*National Standards for Residential Services for Children and Adults with Disabilities* require updating.<sup>(14)</sup>

In 2021, HIQA developed a set of principles to underpin all national standards for health and social care services.<sup>(15)</sup> The four principles of a human rights-based approach, safety and wellbeing, responsiveness, and accountability, work together with the goal of achieving person-centred care and are used as HIQA's standards development framework.<sup>(15)</sup>

The scoping review, to which this protocol applies, aims to identify and describe how peer-reviewed literature characterises person-centred care for children and adults with disabilities living in residential services. This scoping review is intended to inform a potential update of the *National Standards for Residential Services for Children and Adults with Disabilities*.<sup>(14)</sup>

## 1.1 Review question

How does the peer-reviewed literature characterise person-centred care for children and adults with disabilities living in residential services?

### **Specific question:**

What are the characteristics and definitions of person-centred care in residential services for children and adults with disabilities?

## 2. Methods

The scoping review will be conducted in accordance with the Joanna Briggs Institute (JBI) methodology for scoping reviews and reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for scoping reviews (PRISMA-ScR).<sup>(16,17)</sup> The protocol has been registered with Open Science Framework.<sup>(18)</sup>

As it is a scoping review, it will be designed to identify the range of the available evidence, and will be presented as a mapping of the identified data, without particular reference to methodological quality of the sources of evidence.<sup>(19)</sup>

### 2.1 Eligibility criteria

#### 2.1.1 Population

**Inclusion criteria:** Children and adults of all ages with permanent or likely permanent intellectual, sensory and physical disabilities; studies from the perspectives of the service users, their families and residential service staff members.

**Exclusion criteria:** People with age-related disabilities only; children and adults with mental health illnesses only; patients receiving palliative care or people at end of life.

#### 2.1.2 Concept

**Inclusion criteria:** Articles reporting on person-centred care and or patient-centred care.

**Exclusion criteria:** Articles reporting on interventions, treatments, or the use of technological aids, unless they consider person-centred care.

#### 2.1.3 Context

**Inclusion criteria:** All residential services and residential respite services.

**Exclusion criteria:** Home care, domiciliary care, non-residential services care, rehabilitation centres and articles focused on primary care, community care, hospital or acute care settings.

Table 1 below outlines the research questions and the population, concept, context (PCC) mnemonic framework.

**Table 1. The research questions and the PCC mnemonic framework**

Research question	Specific question	Population	Concept	Context
How does the peer-reviewed literature characterise person-centred care for children and adults with disabilities living in residential services?	What are the definitions and characteristics of person-centred care in residential services for children and adults with disabilities?	Children and adults of all ages with a permanent, or likely to be permanent, intellectual, sensory and physical disabilities.	Person-centred care or patient-centred care.	Residential services and residential respite services for children and adults with disabilities.

#### 2.1.4 Types of evidence source

The scoping review will consider peer-reviewed literature and will include all study designs. In addition, reviews and systematic reviews that meet the inclusion criteria will also be considered and examined for relevant studies. Study type is included in the data extraction table, so that it can be reflected in the evidence review report.

**Inclusion criteria:** Peer-reviewed literature, all study designs.

**Exclusion criteria:** Non-peer-reviewed literature, protocols.

#### 2.1.5 Time frames

**Inclusion criteria:** Articles published in or after 2013.

**Exclusion criteria:** Articles published before 2013.

There will be no exclusions based on language or publication status (that is published, in press, in progress, or pre-print) for peer-reviewed literature. For documents in languages other than English, DeepL Translate will be used to translate. Table 2 below outlines the eligibility criteria.

**Table 2. Eligibility criteria**

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>Children and adults of all ages with a permanent or likely permanent intellectual, sensory and physical disabilities.</li> <li>Evidence from the perspectives of the service users, their families and residential service staff members.</li> </ul>	<ul style="list-style-type: none"> <li>People with age-related disabilities only</li> <li>Children and adults with mental health illnesses only.</li> <li>Patients receiving palliative care or people at end of life.</li> <li>Evidence focused on outcomes for staff only.</li> </ul>
<ul style="list-style-type: none"> <li>Evidence related to person-centred care and or patient-centred care.</li> </ul>	<ul style="list-style-type: none"> <li>Articles reporting on interventions, treatments, or the use of technological aids, unless they consider person-centred care.</li> </ul>
<ul style="list-style-type: none"> <li>All residential services and residential respite services.</li> <li>For the purposes of this review, the HIQA definition of residential services will be used: A 'residential service' is one that is comprised of both accommodation and care/support services provided to children and adults with disabilities living in residential settings, on a short or long-term basis, whether or not it is their sole place of residence.</li> </ul>	<ul style="list-style-type: none"> <li>Evidence related to home care, domiciliary care, non-residential services care.</li> <li>Articles focused on primary care, community care, hospital or acute care settings.</li> <li>Rehabilitation centres.</li> </ul>
<ul style="list-style-type: none"> <li>Peer-reviewed literature, all study designs.</li> </ul>	<ul style="list-style-type: none"> <li>Non-peer-reviewed literature, protocols.</li> </ul>
<ul style="list-style-type: none"> <li>Evidence published in or after 2013</li> <li>No filters will be applied to the search strategy.</li> </ul>	<ul style="list-style-type: none"> <li>Evidence published before 2013.</li> </ul>

## 2.2 Search strategy

The bibliographic database searching will follow a three-step strategy, as per JBI methodology.<sup>(20)</sup>

The first step will involve undertaking an initial exploratory search of Medline via Ebscohost, Embase and Google to identify key articles on the topic. The terminology



contained in the titles and abstracts and the index terms (subject headings e.g. MeSH) will be analysed.

In the second step, the librarian will develop a comprehensive search strategy using identified keywords and index terms. The search will be run in the following databases: MEDLINE Complete via Ebscohost, The Cochrane Library via Wiley, CINAHL Complete via EBSCOhost, Embase via Elsevier and PsycInfo via Ebscohost.

Appendix 1 outlines the search strategy developed for Medline Complete. The identified keywords and terms will be translated for each included database. A date limit from January 2013 will be applied. Prior to running the search, the search strategy will be peer-reviewed by a Health Service Executive (HSE) Librarian using the Peer Review of Electronic Search Strategies (PRESS) checklist.<sup>(21)</sup>

In the third step, the reference lists of all included sources of evidence will be screened for additional studies using Citationchaser.<sup>(22)</sup>

The literature search will be conducted in February 2025. A search of grey literature will not be included as part of this scoping review, as a separate review of international grey literature will be conducted and published alongside the scoping review.

## **2.3 Evidence selection and screening**

All identified citations will be collected and imported into Endnote V20 and Covidence and duplications will be removed. Pilot screening at both the title and abstract, and full text screening stages, will be carried out in Covidence as per JBI methodology to ensure consistency across the review team.<sup>(20)</sup> Once 75% agreement is reached in a pilot, the full screening process will commence. For titles and abstracts that appear to meet the inclusion criteria, full text articles will be retrieved and screened against the inclusion criteria. Two reviewers will work independently to review articles and will meet to discuss the results; any disagreements that may arise between the reviewers at each stage of the screening process will be resolved through discussion. If consensus cannot be reached on an article, it will be referred to a third reviewer.

The articles that meet all inclusion criteria will be included in the review. Reasons for exclusion of full texts will be recorded and reported. The results of the search and the article inclusion process will be fully reported in the final scoping review and presented in a PRISMA flow diagram.

## **2.4 Data extraction**

Data extraction will be completed using Microsoft Excel with a template and guidance form designed for this review, as per the JBI scoping review methodology

(Appendix 2).<sup>(20)</sup> Bibliography information about the article will be identified, as well as findings relating to the population, context, concept, the research questions and the four HIQA principles of person-centred care.

A pilot of the data extraction exercise will be independently undertaken by two reviewers on 10% of the articles, in order to calibrate the reviewers and test the template. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The data extraction of the remaining articles will be undertaken by one of two reviewers. A third reviewer will check 20% of all charted data to ensure it is accurate and complete.

## 2.5 Data analysis and presentation

The data will be presented in diagrammatic or tabular form and a narrative summary will describe how the results relate to the research question. The results will be reported using the PRISMA-ScR guidelines.<sup>(23)</sup> The data will be presented as mapped to the four HIQA principles of person-centred care, including a human rights-based approach, safety and wellbeing, responsiveness, and accountability.<sup>(15)</sup>

## 2.6 Dissemination

Dissemination of the results is planned through publications on HIQA's website, conference presentations, and HIQA provider forums. It is intended to use the scoping review findings to inform whether an update of the *National Standards for Residential Services for Children and Adults with Disabilities* will be conducted at this time, and the content of the standards, if updated.<sup>(14)</sup>

### 3. Discussion

The scoping review will provide an overview of the characteristics and definitions of person-centred care in residential services for children and adults with disabilities. The findings from this review will be mapped to the four HIQA principles of person-centred care to inform a potential update of the 2013 *National Standards for Residential Services for Children and Adults with Disabilities* in Ireland.

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## Appendix

### Appendix 1. Search strategy for Medline

Database Name	Medline via Ebscohost
Date search was run	18 February 2025

#	Query	Limiters/Expanders	Results
S1	(MH "Persons with Disabilities+")	Expanders - Apply equivalent subjects	76,962
S2	(MH "Intellectual Disability+")	Expanders - Apply equivalent subjects	109,337
S3	(MH "Communication Disorders+")	Expanders - Apply equivalent subjects	71,353
S4	TI Disable* OR AB Disable*	Expanders - Apply equivalent subjects	30,533
S5	TI disabilit* OR AB disabilit*	Expanders - Apply equivalent subjects	269,578
S6	AB ( (intellect* OR cognitive OR learning OR physical* OR mental*) N3 (deficien* or difficult* or disab* or disorder* or handicap* or impair* or incapacit*) ) OR TI ( (intellect* OR cognitive OR learning OR physical* OR mental*) N3 (deficien* or difficult* or disab* or disorder* or handicap* or impair* or incapacit*) )	Expanders - Apply equivalent subjects	311,915
S7	S1 OR S2 OR S3 OR S4 OR S5 OR S6	Expanders - Apply equivalent subjects	703,211
S8	(MH "Residential Facilities+")	Expanders - Apply equivalent subjects	60,423
S9	(MH "Nursing Homes+") OR (MH "Respite Care")	Expanders - Apply equivalent subjects	47,259
S10	AB ( (residential OR nursing) N1 (home* or facilit* or setting* OR centre* OR center* OR service* OR institution*) ) OR TI ( (residential OR nursing) N1 (home* or facilit* or setting* OR centre* OR center* OR service* OR institution*) )	Expanders - Apply equivalent subjects	60,569
S11	(TI "care home*" OR "respite care" OR "supported accommodation") OR (AB "care	Expanders - Apply equivalent subjects	8,002

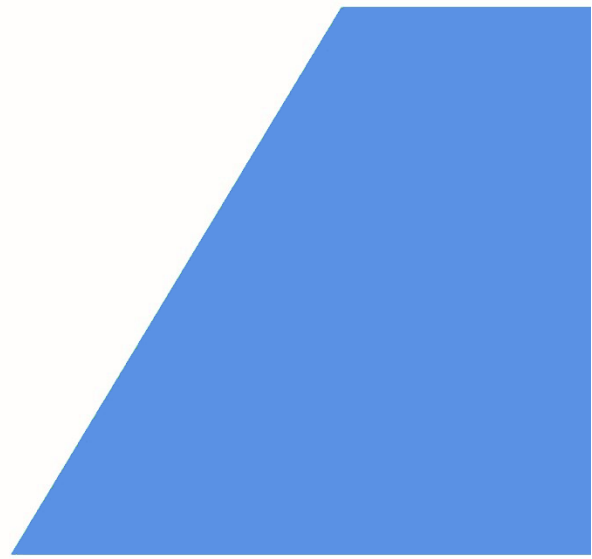
	home*" OR "respite care" OR "supported accommodation")		
<b>S12</b>	AB ( ("continuing care" or disabled or "long term care") N2 (lodge* or facilit* or home* or residence* or centre* or center*) ) OR TI ( ("continuing care" or disabled or "long term care") N2 (lodge* or facilit* or home* or residence* or centre* or center )	Expanders - Apply equivalent subjects	10,379
<b>S13</b>	S8 OR S9 OR S10 OR S11 OR S12	Expanders - Apply equivalent subjects	102,105
<b>S14</b>	(MH "Patient-Centered Care+ ")	Expanders - Apply equivalent subjects	25,892
<b>S15</b>	AB ( (patient* or person or people or individual or "service user" or client) N3 (tailor* or centered or centred or centric* or focus* or oriented) ) OR TI ( (patient* or person or individual or "service user" or client) N3 (tailor* or centered or centred or centric* or focus* or oriented) )	Expanders - Apply equivalent subjects	141,863
<b>S16</b>	S14 OR S15	Expanders - Apply equivalent subjects	154,250
<b>S17</b>	S7 AND S13 AND S16	Expanders - Apply equivalent subjects	362
<b>S18</b>	S7 AND S13 AND S16	Limiters - Publication Date: 20130101-	248

## Appendix 2. Data extraction and guidance form

Formatted Reference	Country	Aim/ Objective/ research questions	Study Design	Study Design	From the perspective of...	Populations included in paper	Description of PWD	Age	Context	Includes a definition of person-centred care	Definition(s) of Person-centred Care	Includes descriptions of characteristics	Description (s) of Characteristics	Relevant citations
From Endnote.	Country, where study was undertaken, or affiliation of first author if not a study.	As described by the authors.	Dropdown menu options:  Quantitative  Qualitative  Mixed-methods  Review  Other.	Free text or copy a brief description	Dropdown menu options:  Person with a disability  Family member  Staff in residential service  Multiple perspectives  Other.	Capture all populations included in the article.	Free text or copy a brief description.	Dropdown menu options:  Under 18  Over 18  Between 18 and 65  Over 65  Mixed ages  Not reported.	Dropdown menu options:  Institution /congregated centres (10+)  Smaller settings (<10)  mixed settings  unclear  respite service  Other.	Dropdown menu options:  Yes  No  Unclear	Free text or copy a brief description.  Enter "not reported" if no definition is provided.	Dropdown menu options:  Yes  No  Unclear	Enter free text.  Enter "not reported" if no specific characteristic is identified.	Add details of any particularly relevant citations.







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